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## Greater Iowa Chapter News

Published quarterly for caregivers, donors, volunteers, advocates and friends in the Alzheimer community

Fall 2006

www.alz.org/greateriowa  
1 800 272 3900

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## Alzheimer's Research and Clinical Trials

The Alzheimer's Association believes that research to prevent, delay onset, or slow progression of dementia before the advanced stage is among the most pressing medical imperatives of the twenty-first century. One of the key components to research is the use of volunteer participants, many of whom have been diagnosed with Alzheimer's disease. Clinical studies are happening every day in all corners of the world, and the goal of the participants, scientists and researchers is that every drug therapy tested or testing procedure that is refined will be the key that unlocks the mysteries of dementing illness.

**What is a clinical study?** Any medical research project involving human volunteers. Scientists work constantly to find better ways to treat, prevent and



diagnose disease. Research into improved approaches usually begins with laboratory work or animal studies. Following early success with these methods, new strategies must demonstrate their effectiveness in the final proving ground of human testing.

**A clinical trial** is a specific type of study in which one group of volunteers gets an experimental treatment, and a similar group gets a placebo. Scientists evaluate the effect of the new treatment by comparing

*Clinical Trials...continued on page 3*

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## Alzheimer's and the Holidays

Holidays can be a wonderful time to reconnect with friends, family and neighbors. It can also be a time of great stress for someone with Alzheimer's disease and caregivers. The Alzheimer's Association has information on activities, safety and gifts suggestions for the caregiver and person with Alzheimer's or other dementia (PWD) that can help make this special time the best it can be.

### Preparing the person with Alzheimer's:

- Talk about and show photos of the people who are coming to visit.
- Have a "quiet" room in case things get too hectic and have a familiar person stay with them so they don't feel isolated or "left out".
- Play familiar music and serve favorite traditional holiday foods.

### Preparing visitors:

- Encourage them to visit, but to also call ahead and arrange a good time to come.
- Familiarize visitors with behavior and condition changes of the PWD.

*Holidays...continued on page 2*

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*Holidays...continued from page 1*

- Celebrate early in the day or have a luncheon rather than dinner, when everyone is more tired and sundowning behavior is more likely.

**Selecting activities:**

- Decorate cookies.
- Stuff, seal or stamp holiday cards.
- Set table and fold napkins.
- Polish silver.

**For those in a care facility:**

- Don't expect loved ones to participate in their old roles.
- Read holiday stories, play music or sing carols.
- Join in with the facility's scheduled activities.

**Safety issues at home:**

- Don't use blinking lights.
- Avoid using decorations that look edible.
- Create a clear path for walking; avoid wires, cords or throw rugs.

For more detailed information regarding Alzheimer's and the holidays, please call our 24-hour helpline at 1-800-272-3900.

**Association Awards Research Grants**

The Alzheimer's Association's 2006 research program funded 96 grants. These projects include:

- earlier detection, imaging and biomarkers
- disease mechanisms
- next-generation therapeutic targets
- lifestyle and environmental issues, genetics and other risk factors
- assistive technologies
- prevention strategies

The 2006 portfolio also includes the Association's largest award ever, a \$2.1 million grant to the Alzheimer's Disease Neuroimaging Initiative (ADNI). This funding will expand ADNI to include PET scans using Pittsburgh Compound B (PIB), a promising amyloid imaging agent that may help to detect Alzheimer brain changes sooner, provide earlier diagnosis, and monitor response to and effectiveness of treatments.

*Clinical Trials...continued from page 1*

outcomes in the two groups. The U.S. Food and Drug Administration (FDA) has established a rigorous sequence of phases for testing experimental treatments. The system gradually builds evidence for effectiveness and determines that the therapy has an acceptable “safety profile” (that is, the risks associated with its use are reasonable given its potential benefit). For more information on the phases of clinical trials, please see the box below.

**What to expect in a clinical trial**

The FDA requires potential participants to be given complete information about the study in writing. In the case of an individual with Alzheimer’s, often he/she has given consent to participate in research through an advance directive, a legal document that allows a person to state wish for future medical decisions. If the person is unable to give consent, it is the responsibility of the surrogate overseeing care to make this decision, based on principals including accurate facts about risks and potential benefits, their loved one’s well-being and judgment of the individual’s best intentions.

**Getting involved**

If possible, discuss involvement in clinical studies with the person with dementia. Making the decision to become involved or abstain from medical research one of the choices that should be made in the planning process. For information on clinical trials, go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov),

a website offered by the National Institute of Health, detailing clinical trials by condition, location, sponsor or status.

The National Cell Repository for Alzheimer’s Disease is recruiting families for two ongoing studies. The first study needs families with two biologically related members who are still living and affected with Alzheimer’s (early or late onset) or other related dementias. Family members will be asked for blood samples to obtain DNA for genetic research.

The second study has more specific enrollment criteria. Families with two siblings who are still living and affected with late onset Alzheimer’s (symptoms developed after age 60) and a third closely related family members that is either affected with Alzheimer’s and over the age of 50 or unaffected and over the age of 60 are needed. If you are interested in either of these studies, please call the National Cell Repository at 1-800-526-2839.

**Phases of clinical trials**

Preclinical studies in the laboratory establish a scientific basis for believing a treatment is reasonably safe and may be effective.

**Phase I trials-** first stage of human testing. Typically enrolls fewer than 100 volunteers.

**Phase II trials-** enroll up to a few hundred volunteers with the condition the drug is designed to treat. Focus on determining safety and best dose of drug. Generally too small to provide clear evidence about benefits.

**Phase III trials-** several hundred to thousands of volunteers, at multiple study sites. Provide chief evidence of safety and effectiveness that the FDA will consider in the approval decision.

**Phase IV trials,** also called post-marketing studies, often required by the FDA after a drug is approved. Gives further insight into long-term safety and effectiveness.

The process of developing and testing a new drug is a lengthy one. The FDA estimates that it takes a little over eight years to test a drug, including early laboratory and animal testing, before there is final approval for use by the general public. There are at least nine drugs undergoing Phase III clinical evaluation right now, with hundreds more clinical trials presently taking place.



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**Thanks to the walkers, donors and sponsors who helped raise over \$513,000 for programs and services provided by the Greater Iowa Chapter!**



Walkers pass under a balloon arch in Des Moines



Cy, the Iowa State University mascot, greets walkers in Ames

**Thanks to our media sponsors:**

Ames Tribune, Carroll Co. Review, Clear Channel Radio, Clinton Herald, DMAQ, Dispatch/Argus/Leader, Dubuque Advertiser, 50+ Magazine, KASI, KAT-FM, KDST, KDTH AM, KGGR, KIMT, KRIB, KROS, KTLB, KWQC TV-6, Mason City Globe Gazette, Mature Focus, Mediacom, Mt. Carroll Mirror Democrat, Northwestern Illinois Dispatch, The Prairie Advocate, Quad Cities Radio Group, The River 101, Savanna Times Journal, Shopper Spree, Telegraph Herald, WCCI, WOI-TV, WOW-FM, 97.3 The Hawk

**Top Fundraising Individuals and Teams**

**Ames**

Corporate Team: Iowa Veteran's Home - \$3,063  
 Family Team: Team CAT - \$5,605  
 Individual: Shirley Stakey - \$3,063

**Carroll County**

Top Team: Big Meadows - \$721  
 Individual: Sandy Harper - \$500

**Clinton**

Team: The Alverno - \$2,171  
 Individual: Don Krambeck - \$4,295

**Des Moines**

Corporate Team: HyVee -\$19,037  
 Family Team: WLYS - \$6,520  
 Individual- David Bailie - \$18,677

**Dubuque**

Corporate Team: Mount Carmel/Sisters of Charity, BVM - \$8,188.56  
 Family Team: The Gross/Manternachs - \$4,136.40  
 Individual: Dave Tranel - \$3,149

**Fort Dodge**

Team: Friendship Haven - \$880  
 Individual: Diane Rollins - \$437

**Humboldt**

Team: Humboldt Care Center North - \$3,144

**Jackson County**

Team: CRS (Can't Remember Stuff), - \$4,000.60  
 Individual: Diane Ploeger - \$1,006.60

**Mason City**

Team: Erickson Team - \$1,178  
 Individual: Ann Kostelnick - \$1,280

**Quad Cities**

Team: Avonlea Cottage - \$6,466.50  
 Individual: Bernard Verschoore - \$3,165

**Sincere thanks to walkers and sponsors in Corning, Lamoni and Montezuma for their support of the Walks in those communities.**

## President Bush Signs IRA Charitable Rollover

On August 17, 2006 President Bush signed the Pension Protection Act of 2006, which permits IRA charitable rollovers or “qualified charitable distributions.” As with most new tax laws, there are many nuances and potential pitfalls. However, the ease of giving and potential income tax benefits makes this an attractive option for many. The following are highlights of the new law:

- ◆ IRA owners age 70½ and older are eligible to rollover up to \$100,000 in 2006 or 2007 to a public charity such as the Alzheimer’s Association. The \$100,000 limit is per donor, so a couple may be able to donate up to \$200,000 assuming each have sufficient funds in their respective IRA’s. (Private foundations, donor advised funds, supporting organizations, or deferred gift plan are not eligible)
- ◆ Qualified charitable distributions from IRA’s will NOT be included in the donor’s federal taxable income.
- ◆ It is not necessary for the donor to itemize deductions and the general 50% of adjusted gross income limitation does not apply.
- ◆ Qualified charitable distributions by December 31 of this year will qualify for all or part of the IRA owner’s required minimum distribution (“RMD”) for 2006.
- ◆ The transfer must be made directly from the IRA to the charity. The specific transfer and reporting forms will be determined by each IRA custodian and the IRS.
- ◆ The entire distribution to the charity must qualify for a charitable deduction – no “quid pro quo” transfers.

### Donor Benefits of the IRA Charitable Rollover:

- ◆ **Convenience:** An easy and simple way to support your favorite cause such as the Alzheimer’s Association.
- ◆ **Lowers Taxable Income:** The donor does not have to include the qualified charitable distribution as taxable income – whether the donor uses the standard deduction or itemizes deductions.
- ◆ **Ability to make larger deductible gifts:** A donor is not restricted to 50% of adjusted gross income by using an IRA for charitable gifts. Therefore, a donor may make larger charitable gifts.
- ◆ **Income tax savings:** The donor may save substantial income taxes not otherwise available due to deduction floors and phase-outs at higher income levels.

The new legislation encourages charitable contributions and provides donors a limited time opportunity to maximize charitable contributions. Done correctly, the donor and the Alzheimer’s Association receive substantial benefits. As with any tax strategy, please consult your professional tax advisor. For more information on charitable rollovers, planned gifts or other ways to support the Alzheimer’s Association, please contact Development Director Lisa Stephany at (515) 440-2722.

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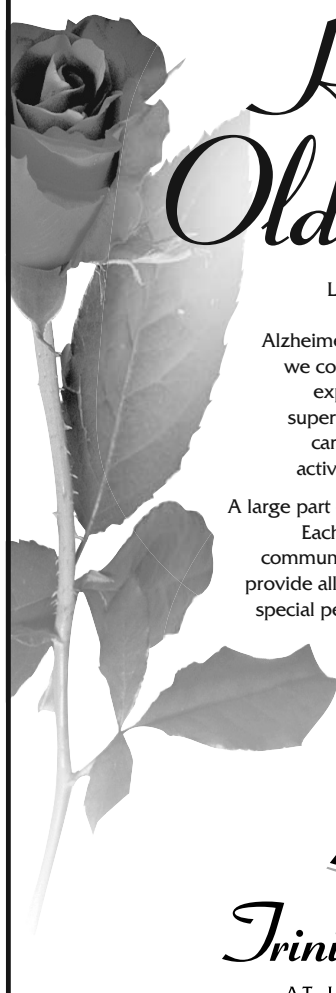
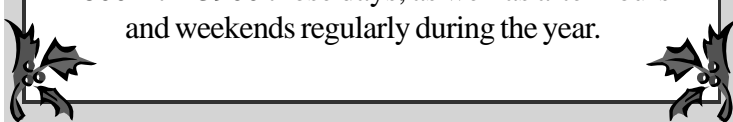
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**Holiday Office Hours**  
All offices of the Greater Iowa Chapter will be closed Monday, December 25 and Monday, January 1. The 24-Hour Helpline will be available by calling 1-800-272-3900 those days, as well as after hours and weekends regularly during the year.




*Health Care  
Older <sup>for</sup> Adults*

Located amidst thousands of roses, our 120-bed facility offers both general nursing care and Alzheimer's care. Care is designed to fit each person as we consider each individual's own "Life Story" – their experiences, abilities and needs. Here, with close supervision and encouragement from compassionate caregivers, residents can continue to participate in activities that give their lives pleasure and meaning.

A large part of what makes Trinity Center special is our staff. Each staff member, selected to be a part of our care community, is carefully screened. Equally important, we provide all staff members with ongoing training. It takes a special person to join the staff of Trinity Center, someone for whom this is not merely a job, but a commitment. Not surprisingly, residents, their families, and our staff members form close relationships, developing what can best be described as a caring community.

  
**Trinity Center**  
AT LUTHER PARK

1555 Hull Avenue — Des Moines, IA 50316 — p: 515-262-5639  
f: 515-266-2688 — [www.luthercareservices.org](http://www.luthercareservices.org)



## Alzheimer's Disease... Sharing the Care

The Greater Iowa Chapter offered its first conference exclusively for family caregivers on November 7, 2006. The program focused on resources for families to support caregiving. Susan Schultz, MD, Associate Professor of Psychiatry, University of Iowa College of Medicine began the conference by discussing Alzheimer's, its stages and common psychiatric symptoms. Why and when to seek assistance and what types of help might be beneficial in various stages of the disease was presented by Ann Riesenberg, Program Director. Joel Fry, LISW from Team Restoration Ministries described the value of meetings to unite family members around caregiving goals and challenges. The need for self care and strategies for caregiver well-being were explained by Nancy Carrick, BSW, Program Specialist, Greater Iowa Chapter and the day concluded with Connie Lucas, Program Specialist, also from the Greater Iowa Chapter, demonstrating ways to connect with loved ones through activities.

Support group facilitators in attendance were acknowledged by Carol Sipfle, Executive Director, during the conference luncheon and the Jurassic Larks, an international award-winning men's barbershop quartet sang parodies about aging to the melody of popular songs.

We gratefully acknowledge the following:

Sustaining Sponsor - Hospice of Central Iowa

Supporting Sponsors - Mercy Hospice, Pfizer, Senior Suites of Urbandale

Through their generosity, we were able to provide quality education for our family caregivers at a nominal cost.

## The Perfect Holiday Gift

Are you looking for the perfect gift for a caregiver of someone with Alzheimer's? Consider the gift of respite. Respite means taking a break-getting away from the day-to-day responsibilities of caregiving. Non-stop, 24 hour-a-day caregiving is impossible and unrealistic for any one person. Recognize respite as a dose of preventative medicine for the caregiver. It allows time to recharge, to spend time on personal interests and needs. Time to shop, get a haircut, have lunch with friends, go to the doctor, read a book or even take a nap are all possible through respite.

The Greater Iowa Chapter provides financial support for caregivers needing assistance in paying for adult day services or in-home respite. Your donations to the Greater Iowa Chapter's Caregivers Respite Fund would be the perfect gift during this holiday season, and will be used exclusively for that purpose. Please consider giving the gift of respite so that a caregiver can have some well deserved time off. Donations to the fund should be directed to:

Alzheimer's Association- Caregiver Respite Fund  
1730 28th Street  
West Des Moines, IA 50266



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- **Restorative Programs**
- **IV Therapy**
- **Secure Alzheimer's Units**
- **Hospice Care**
- **Respite Care**
- **Bariatric Care**
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**Care Initiatives is the proud statewide sponsor of the Alzheimer's Association Memory Walks!**

www.alz.org  
800 272 3900

We are fighting on your behalf 24/7  
to give everyone a reason to hope.

Greater Iowa  
1730 28th Street  
West Des Moines, IA 50266