

April, May, June 2009

# Volunteer Update

## News and Information for Alzheimer's Association Volunteers

### From the President's Desk

#### Welcome Spring with a Fresh Start - Reconnect at Our Open House!

Our new building is finally complete and our staff is settled in. Now we're inviting everyone to come and take a look. **On April 16, from 3-7 p.m. we'll be hosting an Open House at our new location.** Volunteers can come enjoy refreshments and have a tour of our beautiful new facility.

This space is not just ours – it also belongs to you, our volunteers. I hope you will take this opportunity to come see how you have enabled the St. Louis Chapter to grow and better serve our Alzheimer community.

Besides our Open House, we have several events coming up this quarter. We just returned from Memory Day in the Missouri Capital and Advocacy Day in Illinois where we spoke with legislators about our mission and Alzheimer issues. Next we'll host A Night to Remember wine event on May 1, at The Munny in Forest Park.

Then, on May 2 at the University of Missouri – St. Louis, we'll be introducing our Healthy Brain Workshop aimed at African Americans, who are at a disproportionately higher risk for heart disease. The workshop will focus on the brain-body connection. Local experts will offer information on how to get – and stay - healthy.

We also invite volunteers to join us for our Annual Joanne Parrish Knight Caregiver Conference. This

year's conference will be held May 28 at the Ethical Society of St. Louis. *That Uppity Theatre Company* will use performance as an educational tool to nurture awareness, promote insight and empower.

Then, on June 5, it's back to fun and fundraising at our biggest event of the summer – Summer Memories. The Young Ambassadors committee will be hosting the evening at Grant's Farm again this year and guests will enjoy music, food, and Anheuser-Busch products. There will also be a silent auction and lots of wonderful raffle prizes.

We have a full calendar at the St. Louis Chapter this spring and we hope you will join us for as many events as possible, beginning with our Open House.

Sincerely,  
Joan D'Ambrose, Chapter President

### Chapter News & Events

#### SEMO Care Conference: April 24

Please join us for the Southeast Missouri Care Conference scheduled April 24, 2009 at The First Baptist Church, 11 West Castor Street, Dexter, MO.

The event is for both family and professional caregivers. We will cover many topics including: stress management, activities in the home, understanding hospice, understanding behaviors and improving communication, and culture change. Mary Coats, BS, CS, GCNS, MS, RN, of the Alzheimer's Disease Research Center at Washington University School of Medicine will be the keynote speaker.

Registration begins at 8:30, and the program runs from 9:00–3:00 p.m. Admittance is free and a continental breakfast and lunch will be served. To register call 1-800-272-3900 or go to [www.alzstl.org](http://www.alzstl.org).

## **Healthy Brain Workshop: May 2**

Join us for this informative and interactive free-half day workshop to receive first-hand information from local experts on how to get-and stay-healthy. The target audience for this workshop is African-American Baby Boomers but everyone is welcome to attend.

The event features Vickie Newton, news anchor of KMOV-TV News Channel 4 as moderator, and Dr. Valerie Walker, M.D., host of House Calls with Dr. Valerie Walker, as keynote speaker. Details are below, and advanced registration is required.

Saturday, May 2, 2009, 7:30 a.m.-1 p.m.  
University of Missouri-St. Louis  
Bellerive Hall Chapel, 3036 Bellerive Hall  
St. Louis, MO 63121

Continental breakfast and lunch will be provided. To register for this **free** workshop, please visit [www.alzstl.org](http://www.alzstl.org) or call our registration line at 314-801-0452.

## **HBO Series *The Alzheimer's Project*: May 10**

Maria Shriver hasn't just been tending to her First Lady of California duties. She's been busy as executive producer of *The Alzheimer's Project*, a multi-platform series that will look at groundbreaking discoveries made by the country's leading scientists, as well as the effects of the disease both on those with Alzheimer's and on their families. HBO has just announced that the first of four documentaries in *The Alzheimer's Project*, *The Memory Loss Tapes*, will air the week of May 10th. Please check your local listings for more details.

For any interested viewers who do not subscribe to HBO, some areas are allowing for limited community use to ensure anyone who wants to see the films are able. Contact your local cable provider for more information and to see if your area is eligible.

## **Caregiver Retreat: May 22**

Mark your calendars for the annual Caregiver Retreat co-sponsored by the Alzheimer's Association and Mid-East Area Agency on Aging. Caregivers can look forward to a day of fun and pampering. Clayton on the Park, a Sunrise Living Community, is graciously allowing us to use their beautiful facility. Caregivers will be able to enjoy the relaxing view of Clayton Park from our meeting space. The day will include lounging on the huge balcony, listening to entertaining speakers, enjoying a shoulder massage, and savoring a wonderful lunch in the beautifully appointed dining room. Details: Friday, May 22, 2009, 9:00 - 2:30 p.m., 8025 Bonhomme Ave., Clayton, Missouri. Registrations will be accepted April 27-28. Call Lesa at 314-432-3422 for more details or to get the telephone number for registration.

## **Caregiver's Conference: May 28 Volunteers Needed!**

For our volunteers who love to work "behind the scenes," have we got an opportunity for you!

We are currently looking for volunteers to assist with the Joanne Parrish Knight Caregiver Conference. It will be held Thursday evening, May 28 at the Ethical Society on Clayton Road in St. Louis.

The conference will feature a performance from *That Uppity Theatre Company*. The "playback theatre"-style performance will highlight the way caregivers deal with everyday challenges. We need volunteer assistance with the vendor reception, registration, ushering, the *After Glow* reception, and clean up. And then... take a bow as we applaud your contribution to "Setting the Stage for Successful Caregiving!"

Please contact Jennifer Phillips at 801-0414 for more details and to get involved at this great event.

### **Volunteer News**

## **Spotlight Volunteers – Check Them Out!**

New this year, we have profiled a new volunteer per month on our website and in our office as the "Spotlight Volunteer." It is a wonderful opportunity

to know our outstanding supporters better, and to brag about their many accomplishments to the thousands of guests who visit our website each month.

We have been proud to feature profiles on the following volunteers: former practicum student and current education volunteer **Charla Shurtleff**, Franklin County support group facilitator and Memory Walk supporter **Jackie Love-Mueller**, Helpline volunteer and support group facilitator **Jim Miget**, and data entry and Memory Walk volunteer **Jack McCartney**.

Be sure to visit [www.alzstl.org](http://www.alzstl.org) each month to check out the new profile of the month!

### **Volunteer Ambassadors Serve Families – Get Involved!**

Have you known someone facing Alzheimer's who didn't know where to turn? Even though our chapter has been providing free and low cost services for nearly 30 years, many people have yet to hear about everything we can do to help their family. If you believe that no family should fight this disease alone, then we have the perfect volunteer role for you.

Outreach Ambassadors are volunteers who reach out to folks in their local communities. Ambassadors network with people such as neighbors, medical providers, community clubs, local businesses, and even schools. The purpose? To share news about the association and how we are here--ready and willing--to help! The best part is that Outreach Ambassadors have the freedom and flexibility to volunteer on their schedules. Whether you prefer the occasional weeknight, some time on a weekend, or bits of time here and there during the day, ambassadoring is one volunteer role that flexes to fit your schedule.

As our chapter has grown, one constant is the need to reach people who need our help but haven't yet found us. Both in St. Louis and especially in our rural communities, the need for your helping hand has never been greater.

Please consider how becoming an Ambassador could be a dynamic new addition to your schedule. Please call Jennifer Phillips at 314-801-0414 to learn more. The work is rewarding, the need is great, and the time to call is now.

## **Development Update**

### **Help us Celebrate our 20th Anniversary Memory Walk**

It's the 20<sup>th</sup> anniversary of Memory Walk at the St. Louis Chapter! To celebrate, mark your calendar to join us on one of the following weekends:

#### **Saturday, September 12th**

- St. Louis, Forest Park, Upper Muny Parking Lot
- Southeast Missouri, Capaha Park, Cape Girardeau, MO

#### **Saturday, September 19th**

- St. Charles County, Laurel Park, St. Peters, MO
- East Central Missouri, American Legion, Washington, MO

#### **Saturday, September 26th**

- Leadbelt Walk, Bicentennial Park, Bonne Terre, MO
- Illinois Walk, SIUE Campus, Edwardsville, IL

For more information and to register to walk, please call the Memory Walk hotline at 314.801.0440, or at [www.alzstl.org](http://www.alzstl.org).

Until then, we need your help. Volunteers are needed to hang posters around town to help promote the event. Please call Jennifer Phillips at 314.801.0414 if you are able to hang 5-10 posters in your neighborhood. Every bit helps, and we appreciate your outreach and support.

## **Family Services Update**

### **Helpline Office Sees Big Changes!**

The 24-hour Helpline volunteers and staff are excited about their office in the new building. The streamlined office allows community resource materials to be in one central location. Having the volunteers in one area has been conducive to communicating among themselves when they have a question or need input on a call. Thanks to a very generous technology grant, a large screen television has been purchased for training purposes. Everyone

enjoys the windows which provide a sunny, bright atmosphere.

Our location right next to the library allows Helpline volunteers to easily find books, brochures and videos that are useful to families. A volunteer librarian is available to help mail materials.

Monthly trainings are keeping volunteers up to date on Alzheimer's Association programs and services as well as other resources in the community. Recently we have discussed the Centers for Medicare and Medicaid Services' 5 Star Rating on nursing homes (see page 7). Please stop by any time to visit our new office and say hello to our wonderful Helpline team.

## **Principles for a Dignified Diagnosis**

*Principles for a Dignified Diagnosis* is the first statement of its kind written by people with dementia on the subject of the Alzheimer diagnosis experience.

In the 2008 report *Voices of Alzheimer's Disease: A Summary Report on the Nationwide Town Hall Meetings for People with Early Stage Dementia*, the Alzheimer's Association identified diagnostic challenges and dissatisfying interactions with the medical community as two major challenges articulated by people living with AD. These principles are their insights on how to make that experience better.

**Talk to me directly, the person with dementia.** I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.

**Tell the truth.** Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.

**Test early.** Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical trials.

**Take my concerns seriously, regardless of my age.** Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because I am old. At the same time, don't forget that Alzheimer's can also affect people in their 40s, 50s and 60s.

**Deliver the news in plain but sensitive language.** This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.

**Coordinate with other care providers.** I may be seeing more than one specialist — it is important that you talk to my other providers to ensure you all have the information so that changes can be identified early on and that I don't have to repeat any tests unnecessarily.

**Explain the purpose of different tests and what you hope to learn.** Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

**Give me tools for living with this disease.** Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community.

**Work with me on a plan for healthy living.** Medication may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.

**Recognize that I am an individual and the way I experience this disease is unique.** This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.

**Alzheimer's is a journey, not a destination.** Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's.

## **Talking about MedicAlert + Safe Return**

Did you know that we have free MedicAlert + Safe Return registration in our Missouri chapter area, as well as Madison County, IL? If you work in Missouri

(or Madison County, IL) in a care facility, an adult day center, an in-home agency, or a number of other places, you could help all of your residents or clients with dementia to become registered. Call Sarah Stout for a package of brochures.

If you already have MedicAlert + Safe Return materials on hand, please be sure applicants submit their registrations to the St. Louis office (not our Chicago headquarters) to receive free registration.

## Support Group Facilitator Update

### **Meditation: Stress Relief for Support Groups**

As you know, most caregivers carry a high level of stress. A new tool is currently available on our national website which can help caregivers assess their stress. The Interactive Caregiver Stress Check is available at [www.alz.org/stresscheck](http://www.alz.org/stresscheck). Caregivers can fill this out and immediately receive information about available resources. Please share this information with your group members.

There are many positive things that caregivers can do to reduce their stress. One option for stress reduction is to practice meditation. This can be a great support group activity to reduce stress and anxiety, and increase concentration, reduce muscle pain, and increase happiness. There are many types of meditation, so give it a chance. Here are a few meditation techniques that might be helpful for your members. Some of the techniques come from my own background and others come from [www.meditationsociety.com](http://www.meditationsociety.com). While I do not endorse the full website, there might be other ideas that you want to explore.

Each technique generally begins with sitting in a comfortable position in a chair or on the floor. Participants can gently close their eyes and focus on their breathing. Our minds generally wander, which is okay, but try to keep the thoughts coming back to their breathing. After participants have focused on their breathing for a minute or two, go into one of the following techniques.

*Progressive Relaxation:* In this technique, participants will work on relaxing their muscles. First, tell them to clench their fists as hard as they can and hold that for 15 seconds. Then, tell them to relax their

hands and to focus all their thoughts on the feeling of those completely relaxed hands. Then, tell them to flex their arm muscles. Pull them close to their body as tight as they can for 15 seconds. Then tell them to relax their arms and focus on the relaxed feeling. Go through each part of the body in this way. Scrunch up the face and relax. Pull shoulders up to ears. Pull back muscles together. Clench stomach. Flex thighs. Flex calves. Flex feet. At the end, sit for a minute or two and feel the relaxation.

*4-4-8 or Breath Meditation:* In general, most people do not breathe very deeply, and this means that our brains often do not get the oxygen they need. This technique is good for people who only have a few minutes to do an exercise. It can be done just about anywhere, such as watching TV, driving, cooking, cleaning, or sitting quietly. Inhale deeply for four seconds so that your lungs are completely filled and you can see your abdomen expand. While inhaling, imagine that you are inhaling all good things: happiness, smiles, and joy. Then hold this breath inside for four seconds and imagine that all of this goodness is filling every part of your body. Then exhale for a count of eight seconds. While exhaling, imagine that everything bad is leaving you: pain, anger, impatience, guilt, and grief. Do this a number of times.

*Affirmations:* Think of an attribute that you currently desire and focus on it when you inhale. Focus on an attribute that you dislike about yourself or would like to let go of when you exhale. For example, breathing in, think “inhale compassion” and breathing out, think “exhale indifference.” Or inhale tranquility, exhale nervousness. Or inhale peace, exhale suffering. Each member can make up his/her own words for the exercise. Repeat this for a number of minutes.

Meditation can be great to start or end a meeting for anywhere from 5-20 minutes. It could even become a regular part of your meeting if the group members like it. It can help bring a calmer feeling to the meeting and the group members. Many of the meditations can also be done with certain spirituality in mind. If you decide to use a more spiritual meditation or prayer in your group, just be sure that all members are okay with whatever you are using, as you may not know someone’s faith background. It is important that all members feel welcomed.

For other ideas, please look at the website listed above. Focusing on a favorite relaxing place can be helpful. Listening to a calming song while intentionally breathing can help a person to relax.

There are many more ideas. Please feel free to call me to learn more.

-Sarah Stout, MSW, Family Services Coordinator

## **Group Members as Volunteers**

At each training for new facilitators, we have a panel of volunteers who are either current facilitators or group members. This is often one of the highlights of the training, because new facilitators can ask questions of their peers and get ideas. We keep a small list of group members who have volunteered to help with these. However, the list has gotten small and we are in need of more individuals who might be interested. If you know of members who might want to volunteer in this way, usually no more than once per year, please give their names and phone numbers to Sarah Stout, who can then follow up with them.

## **New Facilitator Training**

We will provide training for new facilitators on Wednesday, June 17<sup>th</sup>, 2009 from 9 a.m. – 3:30 p.m. at the St. Louis office. If you have a new co-facilitator or if you have taken over as facilitator for an Alzheimer's Association Support Group please contact Sarah Stout to be added to the invitation list for the June training. All facilitators must be trained by the association staff.

## **Outreach Update**

### **Outreach Memory Walks Are Award Winners!**

Congratulations are extended to two of our outreach Memory Walks that were recognized with awards at the national Memory Walk training conference in New Orleans.

The first recognition was for the Illinois Memory Walk Committee and staff coordinators Jocelyn Damper and Rachel Luge for increasing their walk revenues by 36%.

Additionally, the Southeast Missouri Walk Committee and staff liaison Lisa Hicks were honored with the Star Award representing areas with populations less than 50,000 residents who demonstrated 5% growth in registered participants, a minimum of 100 participants, and \$120 raised per walker. Way to go!

## **Public Policy Update**

### **Calling New Advocates!**

If you have not already signed up to be an Alzheimer's advocate, the question isn't why not, but **WHEN?**

Advocates live throughout our service area in Missouri and Illinois, and answer the call to contact their local legislators when key policies affecting older adults require attention. Each "call to action" that an advocate receives, usually through email, includes detailed information about what the issue is, who to contact, and even suggestions on what to say. You don't need to be an experienced policy-maker to serve as an advocate....you just need to be passionate about making life better for everyone affected by dementia.

Please read below about some recent activity in the public policy arena. We encourage everyone to get involved....there is no contribution too great or too small, and every voice counts.

Please contact Kevin Messina at 314-432-3422 to learn more about how you can sign up as an advocate and start making a difference.

### **Memory Day Brings Big Success**

The Alzheimer's Association is exceptionally grateful for the strong support demonstrated by our advocates for our annual Memory Day advocacy event. Over 140 volunteer advocates traveled to Jefferson City to meet with legislators and discuss the necessity of a comprehensive Alzheimer's State Plan. The plan would enable the state to build a framework to address the needs of our growing older adult population.

Through everyone's effort, it was a day of many successes. SB176, the Alzheimer's State Plan Task Force legislation, was voted to pass by the full Senate while we were walking the halls of the Capitol.

Additionally, the previously deleted Alzheimer's Service Grants funding was fully restored to \$569,000. Representative Bruns (R-Jefferson City) offered an amendment that was voted on and passed.

Of course, the work is not over. In mid-March members of the Senate Appropriations Committee

will make their own recommendations regarding the state's budget. They will more than likely differ from what the House recommended. To finalize, the House and Senate must agree by the end of the first week in May. Members of Senate Appropriations from our chapter area include: Mayer (Vice Chair), Barnitz, Bray, Dempsey, Green, and Rupp. We visited with a number of these senators in March and must continue our efforts. If you live in any of their senate districts, please contact us to see how you can reach out and discuss funding preservation.

To all those that reached out to members of the House Budget Committee, you truly made a difference. This amendment would not have passed without the support of leadership, especially Representative Stream of Kirkwood. The funding is the backbone of vital support and service programs at Alzheimer's Association chapters throughout the state, and we are grateful to each person who contacted their representative to preserve this important budget allocation.

To learn more about how you can continue the good work that was started at Memory Day, please contact Kevin Messina at 314-432-3422.

## **NIH Amendment Passed**

On February 3, the US Senate passed an amendment to raise National Institutes of Health (NIH) funding by \$10 billion. This investment would support more research on Alzheimer's and other diseases.

The amendment's passage does not guarantee that the NIH funding will be in the final Economic Recovery Act (Senate Bill 1), but we are a step closer. Advocates will continue to receive updates with additional actions to help move this funding forward.

## **Research & Media Highlights**

### **Do You Hold the Key to Unlocking the Mystery?**

Volunteers with Alzheimer's disease, with the support of their family members, are needed to advance our understanding of the impact of Alzheimer's. For example, in the area of clinical trials, researchers have developed many new drugs over the past two decades. These treatments have the potential to significantly impact the Alzheimer disease process. If

we realize the hope these drugs offer, then the focus of treatment can shift from helping symptoms to actually stopping the disease process.

The **St. Louis Alzheimer's Association Research Registry** is for people with dementia caused by Alzheimer's disease, and their caregivers, who are open to participating in Alzheimer's disease studies.

#### **How does the registry work?**

- A person (with or without memory loss) joins the Research Registry by completing a written application and consent form.
- A modest amount of personal and medical information is collected and stored in a confidential, secure database at the Alzheimer's Association, St. Louis Chapter.
- Researchers whose studies are approved through a rigorous screening process can access the database.
- If a person's information matches a study's criteria, the person will be contacted.
- Individuals in the registry may be contacted more than once per year, or not at all, based on their suitability for studies currently available.
- The Research Registry is completely voluntary. The details of the specific study, including risks and benefits, will be explained in full if you qualify. A person may accept or reject any studies for which he may qualify.
- Any medication, treatment, other medical procedures performed during the study is free. In addition, you may be compensated for your participation under the discretion of the specific study which will be clearly outlined when you are contacted by the research group.
- Participants will be contacted by the Alzheimer's Association, St. Louis Chapter, at least once each year and asked whether they wish to continue. A person can withdraw from the registry at any time.
- There is no fee to join.

**What types of studies are underway?** There are many different research opportunities. Here are some examples:

#### Clinical trials:

- A study to evaluate new therapies and assess safety and effectiveness.
- It is possible that a volunteer will receive an inactive treatment (placebo) rather than the candidate drug.

- Many trials require multiple visits, sometimes over months or even years, to the study site.
- An example would be an FDA-approved study of an investigational drug for Alzheimer's.

#### Longitudinal studies:

- This is a long term study that observes the participant over a long period of time that may extend over a decade.
- These studies can be clinical, behavioral or caregiving-related.

#### Behavioral studies:

- These are observational studies where the behavior of the participant in certain situations designated by the research team will be observed.

#### Caregiving research:

- Studies that involve the formal or informal caregivers (family, professionals, etc).

#### Web-based research:

- Online studies that primarily include questionnaires aimed at better understanding the disease and its effects.

**How do I register?** If you are interested in joining the registry please email [researchregistry@alzstl.org](mailto:researchregistry@alzstl.org) for an application, or call 800-272-3900 and ask for Kimberly Johnson.

## **Five-Star Quality Rating System**

As you may know, Medicare recently implemented a new initiative, the Five Star Quality Rating System for Nursing Homes. Below is information from the Centers for Medicare & Medicaid Services (CMS) on the new program. **Please remember that this is just one tool that may be helpful for families when making a nursing home decision.**

- For the first time in the history of Medicare and Medicaid, the federal government has rated the nation's 15,800 nursing homes based on the quality of care they provide. The system assigns five stars to the top performing facilities, down to one star for poor performers.
- Each nursing home is evaluated in three areas critical to assessing quality of care: how the home has scored on the most recent three-years of health inspections, how it performs on quality measures, and its staffing levels. Each area is given a score of one-to-five stars, plus an overall star rating.
- The distribution of overall star ratings is not fixed; the number of nursing homes that have one-star ratings or five-star ratings will change over time. CMS expects the distribution to shift towards a higher number of stars over time, as facilities take quality improvement actions.
- CMS currently updates the inspection data on Nursing Home Compare on a monthly basis and updates the quality measures on a quarterly basis. Data for the Five-Star Quality Rating System will be updated on the same schedule.
- Making a decision about long-term care is difficult for any family. The ratings, as well as the other tools on Nursing Home Compare, provide a first-step for evaluating long-term care options for your loved ones.
- First launched in 1998, the Nursing Home Compare website is designed to help consumers with this difficult task. The introduction of the new Five-Star Quality Rating System takes the wealth of information already on the site and summarizes it in a more user-friendly format.
- The ratings are not meant as a substitute for other actions families must take such as consulting their physician and visiting homes in their area. Families should also use the information they find on Nursing Home Compare to begin a conversation with the facility administrator about plans to improve care in areas of concern.
- The overarching goal of the new rating system is to provide unbiased information for the public on key measures surrounding quality of care. Through public reporting and increased awareness by consumers, facilities will continue to advance the quality of the care they provide, resulting in better health outcomes for all.
- Approximately, three million elderly and Americans with disabilities rely on nursing home care annually (about 1.5 million reside in nursing homes at any one time). This is an extraordinarily fragile and vulnerable population. They – and their family members – must be able to count on nursing homes to provide reliable, high quality care. The new Five-Star Quality Rating System gives families an objective tool for evaluating that care.
- The ratings for each nursing home that participates in Medicare and Medicaid can be viewed by visiting [www.medicare.gov/nhcompare](http://www.medicare.gov/nhcompare) or by calling 1-800-Medicare at 1-800-633-4227.

## **Funding Research Continued to be Priority in 2008**

In fiscal year 2008, the Alzheimer's Association continued to play a leading role in the quest to understand and develop better treatments for Alzheimer's by funding research that will advance knowledge in a diverse spectrum of Alzheimer science and piloting an awareness program in five cities to encourage clinical studies participation.

**We helped advance Alzheimer research by funding more than \$26 million in research initiatives**, including \$25.4 million in grants to 131 investigators. This represents the largest-ever commitment by our annual research grant program, which supports a wide range of research, from basic science studies to studies addressing social and behavioral issues in Alzheimer's. The Association is the largest private supporter of Alzheimer research worldwide and has committed more than \$250 million in research grants since 1982.

## **Position Statement on Generic Drugs and AD**

In Alzheimer's disease, as with any medical condition, physicians consider several factors before deciding which medications will be most beneficial to their patients. When a brand name drug prescribed by a physician becomes available in a generic form, physicians play a central role in deciding whether the patient should switch from the brand name drug to the generic. Four drugs to treat the symptoms of Alzheimer's are commonly prescribed: Galantamine (Razadyne™), Rivastigmine (Exelon™), Donepezil (Aricept™), Memantine (Namenda™).

The patent on Razadyne has recently expired, making it the only commonly prescribed Alzheimer drug now available in its generic form, called galantamine. Because generic drugs are less expensive than brand name drugs, consumers may question whether they can stop their current Alzheimer's disease medication and take galantamine instead. Medication changes should not be made without first consulting your physician.

While the cholinesterase inhibitors Razadyne, Exelon, and Aricept vary little in effectiveness overall in studies involving large numbers of subjects, considerable variability may exist on an individual

basis. Little information is available addressing the value and hazards of switching from one cholinesterase inhibitor to another, and such a change should only be made under a physician's supervision with careful attention to the varying pharmacokinetics (the way the body absorbs, processes and eliminates a drug) of the agents involved.

Generic galantamine may be most appropriate for those individuals currently taking Razadyne and for those who cannot tolerate other forms of cholinesterase inhibitors. While generic galantamine has the same active ingredients as Razadyne, it is not entirely identical to Razadyne, and the patient may notice a difference in effectiveness with the generic product. If, after consulting with one's physician, an individual switches to galantamine, the individual and his or her family must be vigilant in noting any changes they observe with the generic product and communicate these changes to one's physician as soon as possible. Presented with this information, the physician may decide that the brand name product is preferable to the generic product.

Another potential candidate for galantamine is the individual newly diagnosed with Alzheimer's who has no history of cholinesterase inhibitor use. The generic product, due to its reduced price, is an appropriate first-choice therapy. However, if the individual does not experience a beneficial response, a brand name cholinesterase inhibitor may be the next logical choice.

Because the drug Namenda is in a different drug class than Razadyne, Exelon and Aricept, switching from it to any cholinesterase inhibitor — generic or brand name — has a higher likelihood of causing a noticeable change in symptoms. This decision should be considered with caution and only after consulting one's physician.

Historically, physicians have noted a variety of individual responses—both positive and negative—to generic drugs aimed at other health conditions. For this reason, it is critical that physicians and patients continue to have access to the full range of cholinesterase inhibitors now available. Blanket adoption of galantamine over any other cholinesterase inhibitor by prescription drug reimbursement plans and programs is inappropriate. -Adopted January, 2009.

## **Local Research Opportunity: Understanding the Experience of People with Dementia**

With the growing number of people who are affected by dementia, it is important to find ways of understanding their well-being and what activities might enhance their well-being. This research project aims to examine the well-being of people with dementia through structured interviews and examine how people with dementia respond to leisure activity.

What's involved for the person with dementia? He/she will participate in a short drawing activity and answer some questions regarding his/her well-being. Trained personnel from the Psychology Department at Washington University will administer the activity and questionnaires at his/her adult day services center (though other locations may be arranged). The session should take 30-40 minutes, and participants will be provided with a \$10 reimbursement for their effort and time.

Participation is voluntary, and all information remains confidential. Researchers are looking for people with mild to moderate dementia who have adequate vision, hearing, and use of hands. To participate, please call Wingyun Mak, at 314-935-6173.

## **New Report: AD and Dementia Triple Healthcare Costs for People Over 65**

Total healthcare costs are more than three times higher for people with Alzheimer's and other dementias than for other people age 65 and over, according to the Alzheimer's Association's *2009 Alzheimer's Disease Facts and Figures*, released in March, 2009.

According to the report, there are 5.3 million Americans living with Alzheimer's disease. Every 70 seconds someone in America develops the disease and by mid-century someone will develop Alzheimer's every 33 seconds.

In the new report, total healthcare costs are calculated as per person payments from all sources. Medicare payments alone are almost three times higher for people with Alzheimer's and dementia than for others over age 65; Medicaid payments alone are more than nine times higher. With an aging baby boomer

population and the country facing unprecedented economic challenges, it is more important than ever that the Alzheimer crisis be addressed.

People with Alzheimer's are high consumers of hospital, nursing home, and other health and long-term care services, which translates into high costs for Medicare, Medicaid, and millions of families. As families struggle to survive in a deepening recession and states grapple with budget shortfalls, Alzheimer's disease threatens to overwhelm them both.

With family members providing care at home for about 70 percent of people with Alzheimer's disease, the ripple effects of Alzheimer's disease can be felt throughout the entire family unit. According to *Facts and Figures*, in 2008, nearly 10 million Alzheimer caregivers in the U.S. provided 8.5 billion hours of unpaid care valued at \$94 billion.

Alzheimer's is now the sixth leading cause of death in the United States, surpassing diabetes. As deaths from other chronic conditions like heart disease and stroke continue to fall, more Missouri residents will live long enough to develop Alzheimer's disease with profound effects on families and state budgets. To plan for this rapidly growing problem, states need accurate and reliable information about the characteristics and needs of their residents who are coping with Alzheimer's and other dementia. To learn more about this subject, the full text of the Alzheimer's Association's *2009 Alzheimer's Disease Facts and Figures* can be viewed at [www.alz.org](http://www.alz.org).

### **Enclosures**

- None this issue.