

Caregiver Support Groups Offer Help and Hope

A support network can be critical – even life saving – for someone caring for a loved one with dementia. For some, this network is built around family or friends; others find support through their church or community organizations. For many Alzheimer caregivers in Michigan, help comes in the form of a local support group – a place where they can talk with others who know firsthand what they are going through.



Alzheimer's Association

“Joining a support group and talking to people that have been there – giving you advice on next steps, warning you about the next hurdle – can help you to stay cool, focused, and prepared,” said Paul Forringer, a former caregiver and current Alzheimer's Association support group facilitator. “Participation in a support group is beneficial to not only the caregiver, but also to the person with dementia.”

Most caregivers find that a support group provides helpful information on the disease and area services, as well as the reassurance that they are not alone in their situation, explained Kim Walsh, program director for the Alzheimer's Association, Michigan Great Lakes Chapter.

“A strong support system is essential in dealing with this disease and for many individuals, that support system is enhanced and strengthened by

participating in a support group,” Walsh said.

While hundreds of people have found help, hope and friendship through the chapter's 45 area support groups, many will acknowledge that it's not always easy to take that first step.

“Attending a support group for the first time can be a daunting experience and many people are unsure of what to expect,” Walsh explained. “Yet, support group members tell us that the people they meet, the stories they hear, and the

Benefits of joining a support group

A support group can give you an opportunity to:

- share your experiences
- decrease your sense of isolation
- learn from others in your situation
- learn about resources available to you
- receive encouragement and moral support from other caregivers
- get help in a crisis
- receive information on dementia and caregiver issues

emotional support they receive at the group are invaluable.”

Pat Harris, a caregiver and support group leader for the Association's African-American Family Circle, said she has learned a great deal from others in her support group. “We are all walking the same path, but we are on different parts

of the road so to speak,” Harris said. “I'm dealing with a situation where my father-in-law is in the early stages – others in the support group are

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**Alzheimer's Association,
Michigan Great Lakes Chapter Names
Elizabeth Longley President and CEO**

The Alzheimer's Association, Michigan Great Lakes Chapter announced on April 3 the appointment of Elizabeth Longley as president and chief executive officer. Longley brings more than 25 years of experience in non-profit management and fund development to her new position at the Alzheimer's Association.

"Liz's skills are an excellent match for our organization and we are fortunate to have her join our team," said John Seeley, chair of the chapter's board of directors. "She is an enthusiastic and dedicated professional who is committed to helping the Association realize its vision of a world without Alzheimer's disease. She has extensive experience in non-profit management, fund development, and program development and implementation. I am confident that under her leadership we will prosper and meet our challenges in the years ahead."

"I am honored to join the Alzheimer's Association and I look forward to working with the many volunteers and staff for this worthwhile cause," Longley said. "My family has been dealing with this disease for decades and the work done by the Alzheimer's Association is critical to supporting families and ultimately finding a cure for Alzheimer's."

Longley comes to the Alzheimer's Association from Hospice of Michigan-Ann Arbor Region, where she served as director of development and was responsible for donor relations, community relations and fundraising. Prior to her work at



"My family has been dealing with this disease for decades and the work done by the Alzheimer's Association is critical to supporting families and ultimately finding a cure for Alzheimer's." - Liz Longley

Hospice of Michigan, Longley served as a workforce consultant for the state of Michigan. Her extensive professional background also includes serving as president of a private, for-profit company that provides consultation services to non-profit organizations.

Longley holds a bachelor's degree from Marygrove College in Detroit and will complete a master's degree in communication with a focus on organizational, leadership and community communication from Eastern Michigan University in 2006. She completed the Saline Leadership Institute program in January 2006. •

Association Message Boards Connect Caregivers

If you can't find time to attend a community support group, help is just a mouse click away at the Alzheimer's Association's message boards and chat room at www.alz.org. The forums for online conversation allow people to discuss issues and share thoughts and experiences.

The message boards "keep me from putting extra stress on my family," explains one caregiver who posts regularly. "They connect me with other people who know exactly where I'm coming from." She notes there's always someone on the boards who has experienced similar issues or can provide a resource.

The Association's message boards feature many options for communicating with others. Features include:

- **Ease of use** – Post and read messages with ease. All posts appear on one, scannable page.
- **Live chat** – Send instant messages to anyone logged into the chat room.
- **E-mail notifications** – Subscribe to favorite discussions or an entire board. Receive alerts to new messages or a digest of new

messages, based on personalized settings.

- **Polls** – Pose questions to members in a forum. See poll results instantly.
- **Expanded, descriptive forums** – Get to specific discussions and information quickly.

Among the 10 forums are groups for caregivers, health professionals and people with memory loss. Other categories include sections featuring success stories, questions for care consultants and news on Alzheimer medications.

The message boards typically have several threads or discussion groups. After registering with a user name and password, users can post replies to topics or start new subjects. Chat rooms are interactive, online discussions about a specific topic. As the interaction is in real time, everyone who is logged in can see what others type. Participants can also break off and have their own keyboard chat.

To log in directly to the Alzheimer's Association message boards, visit www.alz.org/login.htm. •

Support Groups Offer Help and Hope

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dealing with later stage issues. These group members can be teachers to the rest of us."

Each support group is unique and caregivers may want to attend more than one group before deciding to attend a group regularly. The Alzheimer's Association offers a variety of support groups, including groups for male caregivers, African-American caregivers, and support groups for people with early-stage Alzheimer's disease. All support groups meet monthly and are free and open to the public. To learn more about the caregiver support groups available in your local community, contact the chapter office nearest you at 800.272.3900. •

Resources

Brochures

Caregiver Stress: Respect Your Well Being
Alzheimer's Association, 2005

Especially for the Alzheimer Caregiver
Alzheimer's Association, 1999

Respite Care Guide: How to Find What's Right for You
Alzheimer's Association,
Reprinted 2003

For a list of respite services in your area, call 800.272.3900.

Support Groups

The Alzheimer's Association, Michigan Great Lakes Chapter sponsors 45 support groups within a 23-county region. To locate a support group in or near your community, call 800.272.3900.

To obtain these and other resources, contact the chapter office nearest you at 800.272.3900.



Research News

Is Alzheimer's Undertreated?

Although nearly all individuals with mild to moderate Alzheimer's take at least one drug for another health condition, only about 35 percent have been prescribed one of the standard drugs for early Alzheimer's.

According to a report in *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, only cholinesterase inhibitors are approved by the U.S. Food and Drug Administration and recommended by the American Academy of Neurology to treat mild to moderate Alzheimer's. Commonly prescribed are donepezil (Aricept), galantamine (Razadyne) and rivastigmine (Exelon).

“It's worrisome that nearly two-thirds of those in this study never had the opportunity to try a cholinesterase inhibitor,” says William H. Thies, Ph.D., Alzheimer's Association vice president of medical and scientific affairs. “These drugs are not our final answer to Alzheimer's, but they are what we have to offer now. Not using them raises a red flag about the general state of diagnosis and treatment and whether people are receiving other disease management and support.”

Cholinesterase inhibitors modestly delay worsening of symptoms, on average, for around six months to a year, though there are clinicians who believe some patients may temporarily benefit more dramatically.

For this study—funded by Janssen Pharmaceutica, maker of galantamine (Razadyne)—Mary Sano, Ph.D., and colleagues recruited 2,114 individuals with mild to moderate Alzheimer's at 406 U.S. community medical practices. They wanted to assess how regularly participants took galantamine (Razadyne) and vitamin E when doctors prescribed them. The information obtained from participants and caregivers at the time of enrollment provides this snapshot of community dementia treatment:

- Slightly more than 60 percent of whites had ever taken cholinesterase inhibitors, compared with only 25 percent of participants from other ethnic groups.
- Average participant age was about 78 years; 68 percent were women.
- Average caregiver age was 62; 70 percent were women.
- Nearly half of caregivers were spouses; a third, daughters or sons; 13 percent, other relatives or friends; and 6 percent, paid professionals.
- Primary care physicians diagnosed nearly 65 percent of participants and treated about 60 percent.
- On average, participants were taking five other medications; 95 percent were taking at least one.
- On average, participants had three other illnesses besides Alzheimer's; only 12 percent had no other active illness.
- The most common coexisting illnesses were high blood pressure (about 50 percent), depression (18 percent) and diabetes (15 percent).

What Happens in the Brain of a Person with Alzheimer's Disease?



Find out by visiting **Inside the Brain: An Interactive Tour**, an exciting new feature on the Association's Web site that explains how the brain works and how Alzheimer's affects it. Navigate at your own pace through 16 illustrated screens and follow the colored text that highlights that serve as pathways to key areas and special features of each section.

To take the Inside the Brain tour, visit www.alzmgreatlakes.org.

Aricept Late-stage Study Reports Benefits, Spurs Debate

Donepezil (Aricept), a drug currently approved to treat mild to moderate Alzheimer's, also may help nursing home residents with advanced disease, according to research recently published in *Lancet*.

Study participants on donepezil scored a bit better than those getting a placebo on tests designed to assess the capabilities of individuals with severe Alzheimer's. These tests measure such functions as memory, language, social interaction, eating, bathing, operating water taps and turning on light switches. The average participant age was 85.

The report has triggered debate about whether the higher scores seen with donepezil equate to any meaningful benefit for severely impaired individuals, their caregivers or their families. The boost in scores did not meet thresholds predefined to indicate a likely real-world effect, although they came close and were statistically significant.

“This study compellingly demonstrates the dilemmas of late-stage Alzheimer's,” says William H. Thies, Ph.D., Alzheimer's Association vice president of medical and scientific relations. “There's general agreement that treatment at this stage should focus on quality of life, but reasonable people may differ in how they define quality. Decisions are highly personal, and what people need is good, realistic, clearly presented information about risks and benefits of options. These issues also highlight the importance of creating advance directives to guide decision-making whenever possible.” •

Healthy Foods May Protect Brain

Certain foods not only may cut the risk of heart disease and stroke but also appear to protect brain cells.

In general, dark-skinned fruits and vegetables have the highest levels of naturally occurring antioxidant levels. Such vegetables include: kale, spinach, brussels sprouts, alfalfa sprouts, broccoli, beets, red bell pepper, onion, corn and eggplant. Fruits with high antioxidant levels include prunes, raisins, blueberries, blackberries, strawberries, raspberries, plums, oranges, red grapes and cherries.

Cold-water fish contain beneficial omega-3 fatty acids: halibut, mackerel, salmon, trout and tuna.

Some nuts can be a useful part of your diet, with almonds, pecans and walnuts serving as a good source of vitamin E, an antioxidant.

It's unclear how much of these foods do the most good for your brain. However, a study of elderly women showed that those who ate the most green, leafy and cruciferous vegetables were one to two years younger in mental function than women who ate few of these vegetables. •



14th Annual Alzheimer's Association Dementia Care Conference

Westin Peachtree Plaza Hotel
Atlanta, Georgia

Join us this September to meet colleagues and experts in Alzheimer and dementia care, such as renowned expert on Creativity & Aging Gene D. Cohen, M.D., Ph.D.

Participate in education sessions designed to meet your professional needs, including:


- Early-stage issues
- Creative person-centered approaches
- Late-stage/palliative care
- Innovative models of care

September 11–13, 2006

**The premier
national dementia
care conference
is coming to
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Fight to Restore Federal Funding Passes First Hurdle

The U.S. Senate has overwhelmingly approved additional funding for health and education programs that were slated for deep cuts in President Bush's budget proposal for fiscal year 2007. During debate on the "Budget Resolution" (legislation passed by Congress that sets overall spending limits for federal programs), senators voted 73-27 in favor of an amendment by Sen. Arlen Specter (R-PA) and Sen. Tom Harkin (D-IA) to provide an additional \$7 billion for health, education and labor programs above the president's budget request.

Passage of the Specter-Harkin amendment is a major win in the fight to restore federal funding for Alzheimer research and care programs but is only a critical first step in the long federal budget process. Several hours after adopting the Specter-Harkin amendment, the Senate passed the Budget Resolution bill (S Con Res 83), setting the stage for action in the House of Representatives. We face a similar challenge there to restore funding for Alzheimer research and programs when the House begins debating its version of the Budget Resolution this week.

Alzheimer advocates should thank our Michigan senators, Carl Levin and Debbie Stabenow, for their support of Alzheimer funding, and, at the same time, step up communications with our congressmen regarding the federal budget. •

Public Policy News

More Volunteers Needed at Annual Legislative Day

Make sure your voice is heard – register today for this important event

The Alzheimer's Association's annual Legislative Day is set for Wednesday, May 10, 2006, at the State Capitol in Lansing. With Michigan still facing severe budget constraints, public health programs and services, such as those provided by the Alzheimer's Association, are under attack. The preservation of state funding for Alzheimer programs will be one of the key issues for advocates to focus on this year at Legislative Day. In the past two years, Legislative Day participation has been steady at approximately 85 advocates from around the state. The Association hopes to have more than 100 advocates visit legislators this year to tell their personal stories and emphasize the great need to continue funding for Alzheimer programs and services. If the toll-free Helpline, chapter support groups, and information and referral programs are important to you, please consider registering for this year's Legislative Day.

"With legislators looking for every possible dollar to fill budget gaps, many are questioning the return on investment the State gets from public health education funding," said Sara Duris, state public policy coordinator for the Association. But establishing exact financials to define successful outcomes can be a very subjective process. Duris notes, "Nothing is more powerful than to have real people come to Lansing and tell their elected officials that they have found great value in the Association's programs and give examples from their own lives of what might happen if these services were no longer available."

On May 10, Legislative Day participants will assemble for a short program where they will hear brief remarks from a fellow advocate and a state representative or senator. They will be given talking points, in advance, and will visit their elected officials in small groups to discuss issues of concern to the Association. Beyond the budget, key issues include reform of Medicaid, particularly home and community-based care services; the new Single Point of Entry for the state's long-term care system; and issues surrounding quality of care. Registration for Legislative Day is free and transportation may be available. To find out how you can have your voice heard at Legislative Day 2006, please contact the chapter office nearest you at 800.272.3900. •



Phillip Hofmeister

Chapter News

Register Now for the Seventh Schreiber Memorial Conference

May 16, 2006
Radisson Plaza Hotel
Kalamazoo, Michigan

Don't miss the seventh Schreiber Memorial Conference - one of the best conferences for health care professionals and caregivers in southwest Michigan. The conference will be held May 16, 2006, at the Radisson Plaza Hotel in Kalamazoo. This year's program is designed to meet the needs of a diverse audience of professionals and caregivers. Kathy Laurenhue, M.A., a nationally renowned author and lecturer, will launch the conference theme - **Partnering in Care** - with a keynote presentation on creating meaningful experiences for people with dementia while meeting the needs of care partners. Conference sessions will be led by professionals in the dementia care field and will highlight the unique issues that professional and family caregivers face.

Those attending the Schreiber pre-conference on May 15, 2006 will have the opportunity to take part in the launch of Association's **Foundations of Dementia Care** training designed for direct care staff and supervisors in residential care settings.

To register, call 800.272.3900 for a registration form, or visit the chapter Web site at www.alzmigreatlakes.org. The early bird registration discount ends April 14 and there is still time to reserve your spot as an exhibitor - call today. •

Foundations of Dementia Care Workshop: Enhancing Skills and Enriching Lives

The Foundations of Dementia Care full-day training will be offered for assisted living and nursing home staff in Chelsea on June 1, 2006. The interactive training seminar will teach and reinforce techniques aimed at improving communication, meaningful interactions, and the mealtime experience for residents with dementia. This program is funded in part by the Chelsea Community Foundation Fund of the Community Foundation for Southeastern Michigan.

For more information, contact Cassie Messmer, Education and Training Coordinator, at 734.677.3081 or cassie.messmer@alz.org. •

Chapter Now Serves Allegan and Barry Counties

The two Alzheimer's Association chapters in Michigan - the Greater Michigan Chapter and the Michigan Great Lakes Chapter - recently completed an internal restructuring designed to enhance the Association's effectiveness in serving the thousands of Michigan residents who live with Alzheimer's disease and dementia.

As part of this restructuring, the Michigan Great Lakes Chapter began providing Association services in Allegan County and Barry County on January 1, 2006. Allegan County residents are now served by the chapter's office in Kalamazoo; services for Barry County residents are provided through the chapter's Lansing office. The Association's toll-free Helpline number continues to connect callers with their local office. All services including care consultation, support groups, education programs, and Safe Return are being provided without interruption.

This change supports the Association's mission of providing access to services, information, and training for people with Alzheimer's disease, family caregivers and health care professionals.

The Michigan Great Lakes Chapter has received funding from the Barry County United Way and the Barry County Community Foundation to expand programs and services. The chapter is working collaboratively with the Barry County Commission on Aging, which currently hosts the Association support group and will also support our educational programming. The Area Agency on Aging 3B (AAA) is cosponsoring the support group and providing a facilitator. The AAA is also helping to promote chapter programs. In addition, the chapter established a local dementia lending library and scheduled education programs for this spring at the Commission on Aging offices. •

Join the Fight Against Alzheimer's Disease

Individuals interested in joining the fight against Alzheimer's disease can support the work of the Alzheimer's Association in many ways. Non-financial gifts such as volunteering and participating in our annual fundraising events are invaluable ways to show support for the chapter (see related article below). For those who wish to show their support through a financial contribution, there are many options available including:

- Cash
- Stocks, Bonds, Mutual Funds
- Life Insurance
- Gifts In-Kind
- Real Estate
- Retirement Assets
- Wills

Many of our supporters have found that making a bequest to the Association through a will is one way of fulfilling their commitment to the Association's mission. Many attorneys may have their own style for drafting wills, but the following statement contains the necessary elements for making a bequest to the Alzheimer's Association, Michigan Great Lakes Chapter: *"I hereby give, devise, and bequeath (amount, proportionate share, remainder or specific property) to the Alzheimer's Disease and Related Disorders Association, Michigan Great Lakes Chapter, 107 Aprill Drive, Suite 1, Ann Arbor, MI 48103."*

If you have questions regarding making a bequest or want to learn how you can become an event sponsor, contact the Michigan Great Lakes Chapter at 734.677.3081 •

Don't Miss These Upcoming Special Events

The chapter's 2006 special events promise to be our most exciting yet! Our annual charity golf outing and our Memory Walks offer the perfect opportunity for you and your family to show your support for those affected by Alzheimer's. Mark these important dates on your calendar and call today to register – your support makes all the difference.

Coach Bo Schembechler to Lead Annual Charity Golf Outing

The Bo and Cathy Schembechler Charity Golf Outing to benefit the Alzheimer's Association will be held July 17, 2006, at the University of Michigan golf course. Make plans now to be part of this special summer event. You'll have the chance to meet Bo and Cathy Schembechler and play golf at a top-ranked course. Most importantly, your participation will help support vital program and services for the thousands of local families affected by Alzheimer's. Call 734.677.3081 or visit www.alzmigreatlakes.org today to find out how you can get involved as a sponsor, team or individual golfer.

Join the Walk Millions Will Never Forget

The Alzheimer's Association Memory Walk® is the largest Alzheimer fund-raiser of its kind. Families,

caregivers and advocates, along with community and corporate leaders, take to the streets of their communities to raise funds for local Alzheimer education and support programs. The Michigan Great Lakes Chapter will host Memory Walks in 10 cities this fall. Check the list below for the walk location nearest you and call 800.272.3900 or visit www.alzmigreatlakes.org to find out how you can get involved. •



Ann Arbor	October 1 – Gallup Park
Battle Creek	September 9 – Binder Park Zoo
Branch/ Hillsdale	September 9 – Veterans Memorial Park, Fremont
Jackson	September 24 – Cascades Park
Kalamazoo	September 16 – KVCC Texas Township Campus
Lansing	September 17 – MSU Campus
Mason/Oceana	September 23 – Waterfront Park, Ludington
Muskegon	September 16 – Roosevelt Park Community Center
Newaygo Co.	September 23 – Senior Center, Coldwater
St. Joseph/ Cass	September 24 – Armstrong Field, Three Rivers High School