

## How do I decide it's time to get outside help or begin facility care?

Many families take care of their loved ones with dementia at home for as long as they can. It is often difficult to face the turning point where one recognizes that mounting care demands are straining family resources and/or undermining family relationships. Because family resources and circumstances vary, each family has to make these decisions based on its own situation, wants and needs.



Many factors can complicate the decision. Caregivers may feel guilty for even considering placing their loved one into a facility or for getting outside help. Family members may not have a clear understanding of their family needs, or what services are available to them. Some members may be reluctant to bring "outsiders" into their intimate circle, or may feel a loyalty or obligation to "do it on their own."

"My great-aunt cared for my great-uncle with Alzheimer's disease on her own, even though she was legally blind and getting up in years," says Julie Newquist, Communications Coordinator at the Alzheimer's & Dementia Alliance. "They had no immediate family and having a stranger come in made my aunt too anxious. I was away at college so I couldn't help as much as I wanted to, but I stayed with them on my breaks and other extended family were close by, so they coped with it for several years.

"Finally one day my aunt couldn't get my uncle out of bed, so he quickly ended up in a nursing home that was familiar to the family but not necessarily well-versed in dementia care. Unfortunately, my aunt had moved him in a crisis and didn't have the time or resources to find a more appropriate place after all the changes they had been through."

It's understandable to procrastinate on these decisions because it is so difficult. Sadness, anxiety and guilt on the caregiver's part are normal feelings. But waiting can also make things much harder. Discussing these issues as a family can bring those barriers into the open so the family can move forward with the tasks and decisions that need to be made. The Alzheimer's & Dementia Alliance can help guide your family in these discussions and make plans that fit your needs.

*Continued on page 7*



**WINE & ROSES  
FESTIVAL**

**Saturday, April 9, 2011  
6:30 p.m.  
Gala Tasting and Auction  
Nakoma Golf Club  
4145 Country Club Road  
Madison**

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# From the Director

Dear Friends,

Wisconsin is now in the national news as the state struggles with budget issues. Although collective bargaining is receiving most of the attention, we are very concerned about the future of Medicaid and the innovative Wisconsin waiver programs designed to keep people at home for as long as possible. We want to be sure that funds from the state/federal partnership care for our most vulnerable seniors, including those in nursing homes and community based residential facilities, as Medicaid is the only option for many.



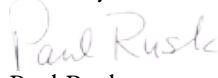
One budget provision concerns us greatly. It would grant the Department of Health Services (DHS) the authority by emergency rule to create policy and funding changes to Medicaid without legislative oversight, which could dramatically impact cost sharing, reimbursement rates to facilities, eligibility levels and benefits. Contact Rob Gundermann at gundermann@alzwisc.org to learn more.

In these challenging economic times, people are increasingly asking questions about how their charitable contributions are used. I'm proud to report, based on recent information provided to the federal government from our audits, that **the Alzheimer's & Dementia Alliance of Wisconsin has the lowest percentage of dollars going to administration and fundraising of any Alzheimer's organization in Wisconsin!** Our percentage is 21.1%. One group we investigated had a fundraising percentage of nearly 90%. Since we are now an independent Wisconsin nonprofit organization and we no longer pay forty cents of every local dollar to a national organization, we anticipate this percentage will decrease next year. We are proud of our low administrative costs and the fact that every dollar you contribute stays in Wisconsin, since both allow us to help additional Wisconsin families.

Charitable organizations need to be clear about the value they provide for the dollars received. Here at the Alliance, our dementia experts provide individualized, local assistance and compassionate guidance to individuals and families to promote the best quality of life during every stage of this challenging disease. Your gifts help guarantee that when people need help – your loved one, friend or maybe even you at some future time – expert staff and in-depth programs and services will be available here in your community to answer the call.

We are dedicated to being an open and affirming organization. Please take full advantage of all that we have to offer, including our upcoming educational events and our popular east and west Madison drop-in programs. We also hope you will consider joining us at our spectacular Wine and Roses event April 9 – see page eight.

Sincerely,



Paul Rusk

P.S. If you receive a solicitation for money that includes a check as a "gift" to you, be aware that cashing that check may authorize a permanent draw from your checking account. We are concerned about the growing number of charity scams. If you receive a letter from the Alzheimer's & Dementia Alliance of Wisconsin with a Segoe Road address in Madison, you are receiving a legitimate request.

# Education programs

Some registration fees may apply.  
Donations are important to continued programming and very much appreciated.

## Family Caregiver Education Series

### West-side Madison

Second Monday of each month, 5:30 - 7 p.m.  
Alzheimer's & Dementia Alliance  
517 N. Segoe Rd., Madison

April 11: Beyond the doctor's office: Issues related to hospitalization and surgery for persons with dementia

May 9: Practical tips for care at home

June 13: Advocating for your loved one in nursing home and assisted living facilities

### East-side Madison

First Monday of every other month, 5:30 - 7 p.m.  
Hawthorne Library  
2707 East Washington Ave., Madison

April 4: Is it time for at-home or facility care?

June 6: Communication tips and strategies

No registration necessary, just drop in.

## Alzheimer's and dementia: Getting started

Tuesday, April 5, 2011, 1 - 2 p.m.  
Richland Hospital, Pippin Room #3  
333 East 2nd Street, Richland Center

Learn about dementia and its warning signs, what to do if you are concerned about yourself or someone you know, and how the ADAW can help. Call Becky DeBuhr at 608.723.4288 to register.

## Maintaining brain health: Tips for staying sharp at any age

Thursday, April 7, 2011, 1 - 2:30 p.m.  
Pioneer Place Apartments  
238 W. Seward, Poynette

Join us for brain health tips regarding nutrition, mental exercise, physical activity and more. Refreshments, handouts and brain teasers provided. Presented by Carol Olson, Alzheimer's & Dementia Alliance. Call Rachel at 608.635.7022 to register.

## Legal and financial planning seminars

Tuesdays, April 19 and 26, 2011  
5:30 - 7:30 p.m.

Alicia Ashman Library  
733 North High Point Rd., Madison  
Guest presenter: Attorney Emily Osborn

Wednesdays, May 18 and 25, 2011  
5:30 - 7:30 p.m.

Behring Senior Center  
1113 10th St., Monroe  
Guest presenter: Attorney Wayne Wilson

Two-part workshop for families providing an overview of legal and financial issues for anyone caring for an older family member. Some of the topics addressed include basic estate planning; advance directives; guardianship; medical assistance; funeral pre-planning; and various ways to pay for long-term care. Call 608.232.3400 or 888.308.6251 to register.

## Taking care of you: Powerful tools for caregivers

Thursdays, April 21 - May 26, 2011  
Time/location TBD, Grant County

Six-session class for family caregivers of older adults who have Alzheimer's or dementia, a chronic disease, long-term illness or disability. It offers tools to improve communication with family members, doctors and service providers, make tough decisions, set goals and much more. A copy of *The Caregiver Handbook* will be provided. No fee. For questions or to register, contact Ruth Rotramel at 608.723.6113 or 800.514.0066.

## Family caregiving: The unexpected career

Thursday, May 5, 2011, 4 - 5:30 p.m.  
Oak Park Place  
800 Waldo St., Baraboo

Caregiving for a family member with dementia is a job we never expected or trained for. Find ways to balance your new responsibilities within your unique family situation. Free. Presented by Carol Olson, Alzheimer's & Dementia Alliance. Light refreshments and handouts provided. Reserve a spot by calling 608.355.4111.

A variety of program choices make a difference for every stage of the journey

## ABCs of Alzheimer's and dementia

Thursdays, May 5 and 12, 2011  
6:30 - 8:30 p.m.

Stoughton Hospital  
Bryant Health Education Center (lower level)  
900 Ridge St., Stoughton

Two-part education series for families of persons diagnosed with Alzheimer's disease or related dementia. Enhance your understanding of the disease, learn how it affects your loved one and how to effectively deal with it day-to-day. Our first session guest is Ken Robbins, M.D. Call 608.232.3400 or 888.308.6251 to register.

Tuesdays, May 10 and 17, 2011  
5:30 - 7:30 p.m.

Richland Hospital, Pippin Room #1  
333 East 2nd Street, Richland Center

Our first session guest is Robert P. Smith, M.D. Call Becky DeBuhr at 608.723.4288 to register.

## We all forget: Is it normal aging or should I be concerned?

Thursday, May 19, 2011, 10:30 a.m. - 12 p.m.  
St. Clare Hospital, Ringling Room  
707 14th St., Baraboo

We all forget names occasionally and misplace keys and wallets. But not all memory glitches signify the start of a progressive disease like Alzheimer's. Learn how our memories work, what's "normal" as we age and what to do if we're concerned for ourselves or others. Presented by Carol Olson, Alzheimer's & Dementia Alliance. The hospital's Golden Care Program will provide refreshments. RSVPs appreciated: 608.356.1407.

## Keeping active: Helping the person with dementia stay involved

Tuesday, June 7, 2011, 1 - 2 p.m.  
Richland Hospital, Pippin Room #3  
333 East 2nd Street, Richland Center

Discover ways to plan for and adapt household routines and to support continued involvement in pleasurable pastimes. Call Becky DeBuhr at 608.723.4288 to register.

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# Research update

## Local research opportunities

### Wisconsin Alzheimer's Disease Research Center (W-ADRC)

#### Neuro-imaging and swallowing

**research study:** We are interested in finding out how our brain works when we swallow liquids of different temperatures and tastes. If you are an adult recently diagnosed with mild Alzheimer's disease; aged 65-85; right-handed; and not claustrophobic (we will be using functional Magnetic Resonance Imaging (fMRI) for this study), then you are eligible to participate.

This study requires 3-4 hours of your time. Participants will earn \$50. If you or anyone you know qualifies for this study and would be interested in participating, contact Georgia Malandraki, PhD, at malandraki@wisc.edu or 608.256.1901, ext. 11125.

**One day study – falls:** The purpose of this study is for researchers to understand how memory changes affect the risk of falling. Participants in this study should be over the age of 65, have a diagnosis of mild cognitive impairment (MCI) or Alzheimer's disease, and be able to walk for three minutes independently or with an assistive device. Your participation in the study will include only one visit to the study clinic that lasts approximately 3 to 3.5 hours. The study includes:

- A brief exam by the study doctor
- Health, mood, and behavior questionnaires
- A walking task (you will be asked to walk down a hallway and perform a thinking task)

- Tests of memory and thinking
- fMRI scan

Call 866.636.7764 or email [wcmp@medicine.wisc.edu](mailto:wcmp@medicine.wisc.edu) if you are interested.

**Wyeth 3001:** The purpose of this study is to determine if bapineuzumab is a safe and effective treatment for Alzheimer's disease. Participants will receive assessments to observe memory, daily activities and other measures of brain function over time, and must have a caregiver attend with them. Bapineuzumab or a placebo will be given by IV. Participation lasts 20 months. Call 608.256.1901, ext. 12919 for more information.

### Wisconsin Alzheimer's Institute (WAI)

As a center within the University of Wisconsin School of Medicine and Public Health, the mission of the Wisconsin Alzheimer's Institute is to create a public health environment in which Alzheimer's disease and related dementias are widely recognized, well understood, aggressively and appropriately treated, and in which those who are afflicted and those who care for them receive the education, quality services and support they need to effectively cope with this devastating chronic disease. For updates on the Wisconsin Registry for Alzheimer's Prevention (WRAP) study, contact Janet Rowley: 608.829.3306; 800.417.4169; [jsrowley@wisc.edu](mailto:jsrowley@wisc.edu).

## Research in brief

### F.D.A. sees promise in Alzheimer's imaging drug

Source: *The New York Times* - An advisory committee to the Food and Drug Administration recommended unanimously that the agency approve the first test – a brain scan – that can show the characteristic plaques of Alzheimer's disease in the brain of a living person. The approval was contingent on radiologists agreeing on what the scans say and doctors being trained in how to read the scans.

“We don't know exactly what the F.D.A. will want,” said Dr. Daniel M. Skovronsky, chief executive of Avid Radiopharmaceuticals. “But it should take months to generate this type of data, not years.” Alzheimer's specialists said they expect that if the scan were approved it would come into widespread use.

Some people have plaque without having Alzheimer's, so if a scan shows plaque, doctors will have to use their clinical judgment in deciding what the scan results mean.

### Financial planning a key but neglected component of Alzheimer's care

Source: ScienceDaily - Patients newly diagnosed with Alzheimer's disease or other dementia and their families need better guidance from their physicians on how to plan for the patient's progressive loss of ability to handle finances, according to a study at the San Francisco VA Medical Center.

“When a patient is diagnosed with Alzheimer's disease or dementia, the chance that their physician will discuss advance planning for finances is min-

iscule,” said lead author Eric Widera, MD, a geriatrician at SFVAMC. “And yet when family members and caregivers are asked what’s important to them, finances are near the top of the list.

“The literature tells us that financial incapacity occurs very early and very rapidly in Alzheimer’s disease and other dementias,” said Widera.

This rapid progression of financial incapacity, said Widera, makes it “essential” that physicians proactively counsel patients and their families on financial planning “early in the disease, while the patient still has the capacity to make the decisions” that will allow trusted caregivers to take over finances.

As a first step in financial planning, the authors recommend that early in the course of the disease the patient sign a durable power of attorney authorizing a family member or other trusted caregiver to make financial decisions on the patient’s behalf.

*Come to one of our Legal and Financial Planning Seminars this spring in Madison or Monroe. See page three for details.*

### **Moderate exercise improves memory in older people**

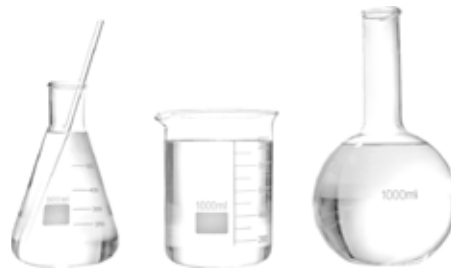
Source: Medical News Today - Just one year of moderate physical exercise in late adulthood can reverse shrinkage of the brain’s hippocampus and improve spatial memory, said US researchers in a new study funded through the National Institute on Aging.

The hippocampus is a significant part of the brain in humans and other mammals. It plays an important role in long term and other types of memory formation and spatial navigation.

As we enter late adulthood, this part of the brain starts to shrink, leading to loss of memory and increased risk of dementia. The researchers found that aerobic exercise training increases

the size of the anterior hippocampus, leading to improvements in spatial memory.

This research shows “...that even moderate exercise for one year can increase the size of that structure. The brain at that stage remains modifiable.”



### **Americans worry about getting Alzheimer’s**

Source: WebMD - American adults fear getting Alzheimer’s disease almost as much as they do getting cancer, a new survey shows.

A survey of 1,007 adults by Harris Interactive for the MetLife Foundation finds that 41% of people fear cancer most, closely followed by Alzheimer’s disease at 31%.

Currently, more than 5 million people have Alzheimer’s, and that number is expected to mushroom in coming years with the aging of the baby boom generation. Though a large number of people fear getting Alzheimer’s, 62% of those surveyed say they know little or nothing about it, which may explain why only 18% of adults have developed a plan for care should they get the disease.

### **An Alzheimer’s vaccine in a nasal spray?**

Source: ScienceDaily - Researchers of Tel Aviv University’s Department of Neurobiology are working on a nasally-delivered 2-in-1 vaccine that promises to protect against both Alzheimer’s and stroke. The new vaccine repairs vascular damage in the brain by rounding up “troops” from the body’s own immune system.

And in addition to its prophylactic effect, it can work even when Alzheimer’s symptoms are already present.

“Using part of a drug that was previously tested as an influenza drug, we’ve managed to successfully induce an immune response against amyloid proteins in the blood vessels,” says Dr. Dan Frenkel, who collaborated on this project with Prof. Howard L. Weiner of Brigham and Women’s Hospital, Harvard Medical School. The vaccine could be given to people who are at risk, those who show very early symptoms of these diseases, and those who have already suffered strokes to repair any vascular damage.

### **High cholesterol and blood pressure in middle age tied to early memory problems**

Source: Medical News Today - Middle-age men and women who have cardiovascular issues, such as high cholesterol and high blood pressure, may not only be at risk for heart disease, but for an increased risk of developing early cognitive and memory problems as well.

For the study, 3,486 men and 1,341 women with an average age of 55 underwent cognitive tests three times over 10 years. “Our findings contribute to the mounting evidence for the role of cardiovascular risk factors, such as high cholesterol and blood pressure, contributing to cognitive problems starting in middle age,” said study author Sara Kaffashian, MSc, with INSERM, the French National Institute of Health & Medical Research in Paris. “The study further demonstrates how these heart disease risk factors can contribute to cognitive decline over a 10 year period.”

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# Public policy issues



## Who funds Alzheimer's research?

A number of foundations, associations and societies provide research funding for Alzheimer's disease. However, none provide more than \$13 million in any given year. The primary source of Alzheimer's research funding comes from the pharmaceutical industry and the federal government. In 2010, the National Institute for Health spent \$480 million on Alzheimer's research. In total, the federal government spends about \$640 million on Alzheimer's research when all agency spending is included.

In Wisconsin, we led a successful fight to obtain \$1.5 million per year for Alzheimer's research funding at the University of Wisconsin. That investment in research funding by the State Legislature paved the way for the creation of the Wisconsin Alzheimer's Disease Research Center at the University of Wisconsin-Madison. When you look at these numbers it reinforces how important our lobbying and public

policy efforts are in maintaining and increasing state and federal Alzheimer's research funding.

## Hope for the future... and expensive research

Today, America's biopharmaceutical companies have 98 new medications to treat Alzheimer's disease in clinical trials or under review by the Food and Drug Administration (FDA). This work indicates a major commitment to Alzheimer's given that each new medication costs, on average, more than \$1 billion to research and develop. In fact, pharmaceutical industry-wide research and investment reached a record \$65.2 billion in 2008. We are extremely hopeful that the next generation of prescription drugs developed to treat Alzheimer's disease will be significantly better than what we have available today.

For further information, please contact Rob Gundermann, Public Policy Director, at [gundermann@alzswisc.org](mailto:gundermann@alzswisc.org).

## AFCSP program exempted from budget cuts!

The Alzheimer's & Dementia Alliance of Wisconsin formally thanked Governor Scott Walker for maintaining the Alzheimer's Family Caregiver Support Program (AFCSP) and for expressly exempting the program from any cuts. AFCSP is the only respite program in Wisconsin designed specifically to allow people with dementia to remain in their homes, where 70% of their care is provided free of cost by friends and family.

The AFCSP is a small program, only \$1.8 million per year, but it saves the state an enormous amount of money by keeping people out of nursing homes, many of whom would be funded through the Medicaid program.

The program served more than 17,000 families coping with dementia in 2009. The average cost of nursing home care in Wisconsin is \$82,125 per year – more if the nursing home resident has dementia. The cost of providing nursing home care for just 22 people for one year costs more than the entire AFCSP allocation of \$1.8 million.

“Governor Walker's actions in maintaining AFCSP will allow many people with dementia to remain in their homes. This will avoid placing an additional burden on the Medicaid program,” said Rob Gundermann, Public Policy Director for the Alzheimer's Alliance. “We're extremely pleased that Governor Walker recognizes AFCSP is a good deal for Wisconsin taxpayers.”

For information on the AFCSP program, contact Mary Kazi, AFCSP Coordinator, at 608.441.8420 or [mary.kazi@alzswisc.org](mailto:mary.kazi@alzswisc.org).

## How do I decide...

*Continued from page 1*

If you are considering outside help or facility placement, remember there is no “right” time for anyone. Consider the following issues for guidance:

**Safety.** Is the home environment becoming more difficult for the person with Alzheimer’s, or is she having accidents or trouble getting around the house?

**Personal hygiene.** Is it difficult for your loved one to get to the bathroom? Is the person unwilling or unable to bathe, change clothing or help with personal care tasks? Have her care needs become too demanding for you?

**Behavioral concerns.** Has your loved one ever wandered away, become combative, suspicious or refused care? Has he physically harmed himself or you?

**Nutrition.** Does your loved one have trouble preparing meals or eating independently? Does she have health problems associated with poor nutrition? Has eating and swallowing become difficult for her?

**Time and energy.** Do you need to help the person with basics like bathing, dressing, and personal hygiene? Do housekeeping duties need to be done so frequently that care becomes an excessive demand? Have you frequently lost sleep at night due to caregiving?

**Caregiver issues.** Do you feel like it’s becoming difficult to make it through another day? Is your health at risk or beginning to suffer because of your caregiving responsibilities? When you get a break from caregiving, do you still feel overwhelmed and exhausted?

Contact the Alzheimer’s & Dementia Alliance for help in evaluating your situation and making these important decisions. We have experienced staff and excellent resources to help you. You may want to attend our monthly education program on Monday, April 4 at Hawthorne Library, “Is it time for at-home or facility care?” (See page three for details.)

Finally, don’t forget to *take care of yourself*. Get regular physicals, eat well, exercise and join in some fun social activities. Consider attending one of our local support groups to minimize feelings of isolation, share stories, get tips and strategies and receive emotional support. It can make a big difference. For a current support group listing, visit our website at [www.alzswisc.org](http://www.alzswisc.org) or call 608.232.3400 or 888.308.6251 toll-free.

*—Excerpted in part from Amelia Schafer and “Alzheimer’s Disease: The Family Journey”*

## Dementia Specialist: Best Practices for Direct Care Staff

This spring the Alzheimer’s & Dementia Alliance will present another Dementia Specialist Training, the two-day interactive workshop developed for direct care staff, long-term care professionals and professionals who work with those who have developmental disabilities and dementia. Staff have the opportunity to learn innovative problem-solving techniques that can prevent challenging behaviors and increase success.

**Tuesdays, May 10 and 17, 2011  
9:00 a.m. - 4:30 a.m. (includes lunch)  
Southwest Wisconsin Technical College  
Fennimore**

This session is hosted by The Grant County Dementia Care Network, which is making a special financial contribution so that we may offer you a discounted registration fee of only \$25 per person – so be sure to take advantage of this special opportunity!

**Advance registration requested by May 6.** Register with Becky DeBuhr, 608.723.4288. For more information, contact Lana Phelps, Training Specialist, 608.661.0463.

## 2011 Alzheimer’s Walk: It’s easy to register online!

**Green: Saturday, September 10**  
Behring Senior Center, Monroe  
[support.alzswisc.org/green](http://support.alzswisc.org/green)

**Grant County, September 18**  
Grant County Fairgrounds, Lancaster  
[support.alzswisc.org/grant](http://support.alzswisc.org/grant)

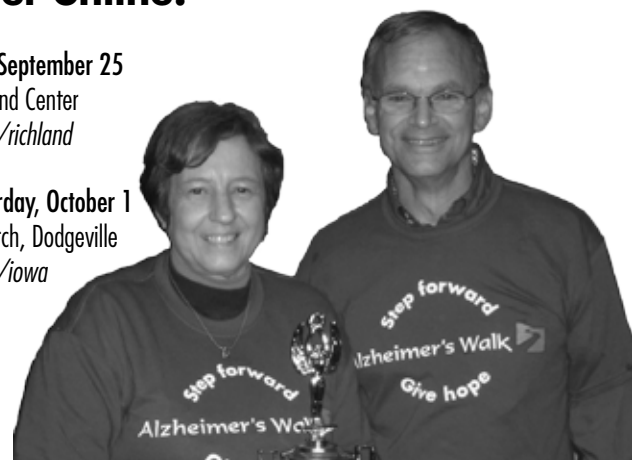
**Richland: Sunday, September 25**  
UW-Richland, Richland Center  
[support.alzswisc.org/richland](http://support.alzswisc.org/richland)

**Columbia: Sunday, September 11**  
Riverside Park, Portage  
[support.alzswisc.org/columbia](http://support.alzswisc.org/columbia)

**Sauk: Saturday, September 24**  
Ochsner Park & Riverwalk, Baraboo  
[support.alzswisc.org/sauk](http://support.alzswisc.org/sauk)

**Iowa County: Saturday, October 1**  
Grace Lutheran Church, Dodgeville  
[support.alzswisc.org/iowa](http://support.alzswisc.org/iowa)

**Dane: Saturday, September 17**  
Warner Park, Madison  
[support.alzswisc.org/dane](http://support.alzswisc.org/dane)



# WINE & ROSES FESTIVAL™



## Fourth Annual Wine & Roses Festival

Saturday, April 9, 2011, 6:30 p.m.

Gala Tasting and Auction  
Nakoma Golf Club

4145 Country Club Road

Tickets: \$95/ person

Raise a glass with our Emcee, Dr. Frank Byrne, President of St. Mary's Hospital, and toast an evening not to be missed. Featuring wine tasting, hors d'oeuvres and live music, there are also live and silent auctions featuring exclusive items, many of them wine related. Winemakers from select vineyards across the country will attend and pour their favorite wines, many not available in our area.

What a memorable way to celebrate spring! We are also looking forward to several new winery guests this year. Guest wineries for the 2011 event are:

- **\*Basel Cellars**  
Walla Walla, WA  
Justin Basel, Winemaker
- **\*Casa Ventura Imports** presenting a selection of Spain's top wines, Bellingham, WA  
Laura Stiff, Special Representative
- **Laetitia Vineyard & Winery**  
Arroyo Grande, CA  
Heather Haehl, Special Representative
- **Ledgestone Winery**  
Greenleaf, WI  
Tim Abel, Winemaker

- **Peterson Winery**  
Healdsburg, CA  
Fred Peterson, Founder and Winemaker
- **Prager Winery & Port Works**  
St. Helena, CA  
Richard Lenney, Winemaker
- **\*Reininger Winery**  
Walla Walla, WA  
Justin Vajgert, Special Representative
- **\*Schug Winery**  
Sonoma, CA  
Alex Schug, Special Representative
- **Sokol Blosser Winery**  
Dundee, OR  
Staci Pettus, Regional Brand Ambassador
- **Wollersheim Winery**  
Prairie du Sac, WI  
Philippe Coquard, Winemaker

*\*New to Wine & Roses in 2011*

For more information, please visit [www.alzwissc.org](http://www.alzwissc.org) or call Miriam Boegel at 608.232.3409.



From l-r: Erin Warren, Michelle Oster, Catherine Olson (Wine & Roses 2010)



From l-r: Miriam Boegel, Michael Muryani, Shelley Muryani (Wine & Roses 2010)

## More special events!

### All proceeds go to Alzheimer's & Dementia Alliance

**Lake Delton: Second Annual St. Patrick's Day Irish Buffet Fundraiser,** Thursday, March 17, 5:00 - 8:00 p.m., House of Embers, 935 Dells Parkway-Hwy 12, Lake Delton. Live music by Random Llama, raffle, prize drawings. \$20/person. Call 608.253.6411 for information or reservations.

**Reedsburg: First Annual Tap Bowling Tournament,** hosted by the Sauk County Health Care Center to raise funds for their Alzheimer's Walk team (see page seven). Saturday, March 19, two shifts: noon and 3:30 p.m., Brewster's Lanes, Reedsburg. \$15/person. Five-person teams. Silent auction and raffles, including Nintendo Wii raffle. To register or for more information, call Brewster's Lanes (608.524.2276) or Margaret Burggraf, Sauk County Health Care Center (608.524.7540).

### Oregon: 15th Annual \$1,000,000 Shoot Out™ Charity Golf Outing,

Monday, August 1, 10:30 a.m., The Legend at Bergamont, 699 Bergamont Boulevard, Oregon. A superb networking opportunity – in 2010, 32 businesses were represented, some with multiple foursomes. Act before July 1 to receive early bird discounts! Call 608.232.3400.



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# For the person with memory loss

We were chatting about communication recently at a Meeting of Minds group, the Alzheimer's & Dementia Alliance of Wisconsin program for people with the early stage of a memory disorder.

Participants were talking about disclosing their diagnoses to relatives and friends, and a wide range of experiences were shared. One participant said that two of her best friends essentially "disappeared" when they learned of her early stage Alzheimer's diagnosis, which was unexpected and painfully difficult to understand. Yet, when she and her husband tentatively told other friends about her memory disorder, hugs were immediately offered as these friends said, "We will be with you through this and we will help you!"

Another participant observed that he thinks many people are still afraid of Alzheimer's disease and consequently they run from it, even when a close friend or a near and dear relative is affected. He has also noticed a peculiar phenomenon: "When people I'm speaking with learn I have Alzheimer's, they start talking LOUDER to me!" Three other group participants burst into laughter, having experienced the same thing.

Meeting of Minds participants agreed that many people seem afraid of being around people who have been diagnosed with Alzheimer's disease or a related disorder. "It's almost as if they think it's catching," one group member observed. That discomfort translates into difficulty communicating with a friend or loved one who has a memory disorder.

How can it be easier? Here are some communication suggestions offered by Meeting of Minders to their friends and family members:



- The use of appropriate facial expressions and hand gestures to emphasize and clarify words that are spoken can make a big difference in the ability of a person with memory loss to understand verbal communication.
- The pacing of a conversation is an important factor. Speaking at a relaxed pace with clearly articulated words helps someone with a memory impairment follow the train of thought. Being observant for cues indicating the person might need clarification or rephrasing is also a good idea.
- When speaking with someone who has a memory impairment, be careful about how you use the word "remember." Saying, "Do you remember that?" or "Don't you remember that?" puts the person with memory loss on the hot seat. As one group participant said, "I start feeling picked on – almost bullied."
- Even worse is, "You probably don't remember, but..." which is pre-

sumptuous and may feel diminishing or disempowering.

- Assuming that a person needs help finding words is not a good thing, even when the intention is to help. Maybe the person with memory loss would appreciate a little assistance finishing the sentence. Maybe not. The important thing is to not be a mind reader and assume that you know best. Ask if help is needed or wanted. Be light-hearted and matter of fact about it. You can trust that the person with memory loss will let you know what they need from you in a conversation.

Finally, one Meeting of Minders said, "The kind of communication I like best is a kiss from my wife!" Certainly a kiss, a hug, a touch on the shoulder, the warmth of a hand can say more than words. And, when we don't know what to say, we can certainly share this: "I wish I knew what to say, but I don't – I just wish we were all young and immortal again. But even if we're not, I can still give you a hug!"

## VOLUNTEER SPOTLIGHT



*Thank you to all of you who do so much to keep our agency running smoothly and to help us expand our services to reach more families. As a way to recognize all of the wonderful things that volunteers do for the Alzheimer's & Dementia Alliance, we "spotlight" a different volunteer in each newsletter.*

Judy Stevenson joined our Public Policy Committee in 1987 when she retired from her career as a clinical nurse specialist in mental health. At that time she also started facilitating an Alzheimer's caregiver support group. She encouraged the caregivers to attend Public Policy Committee meetings and hearings at the state capitol.

Judy has been a tireless advocate for people with dementia and her dedication has been truly inspiring. It takes a very special person to travel across the state to attend a hearing, wait all day to speak and still maintain a positive attitude in front of a legislative committee.

"At one legislative hearing we all wore purple shirts the day of the hearing. We all gained a sense of power by being present to register in support of people with dementia and have the opportunity to testify about the issues affecting our lives as caregivers of a loved one with Alzheimer's disease," said Judy.

Judy explains the reason she has been on the Public Policy Committee for the last 23 years "It's important, it's an honor and it's very rewarding to advocate for those with Alzheimer's disease who are no longer able to advocate for themselves."

We thank Judy for her years of dedication helping to write letters to our legislators, attending meetings and hearings, and advocating for funding for the Alzheimer's Family Caregiver Support Program as well as the increase in dementia training requirements, the creation of dementia specific standards and many other issues.

We especially thank Judy for the wonderful attitude she brings with her and how she brightens the lives of us all. Judy has been an absolute pleasure to work with and we hope we have the opportunity to work with her for many years to come!

## Great strides being made on diversity efforts

On February 19, 2011, we celebrated our first annual Solomon Carter Fuller Memory Screening Day at the Urban League of Greater Madison. I would like to thank our wonderful sponsors for generous donations to this event:



- Madison Gas & Electric Foundation
- Ancora Coffee
- JP Hair Design, Inc.
- Pam Pfeffer, Subway of Cottage Grove
- Crystel Anders
- Madison College
- Mary Kay Baum
- Urban League of Greater Madison

This free memory screening event was held in celebration of Black History Month. We thought it was very important to not only reach out to the African American community, but also to introduce our agency to the community as well.

The event was from 9:00 a.m. - 4:00 p.m. with participants coming in all day to be tested. The generous donation of Mary Kay's book, *Traveling with Hope*, was given out to each participant. The participants shared with me how happy and thankful they were for being able to come to a free screening. Many thanks go out to the students from UW-Madison who volunteered their Saturday to assist the Wisconsin Alzheimer's Disease Research Center and Alzheimer's & Dementia Alliance with the screening.

Secondly, we have lots of exciting news going on in Beloit. An Advisory Committee was established in October, and I now have office space at the Merrill Community Center. We have offered

and conducted caregiver consultations to African American families in Madison and Beloit.

In addition, I have a monthly column in *The Madison Times* newspaper. I have also been invited to various health fairs and community centers to give presentations and workshops. I look forward to developing relationships with the faith communities in Beloit and Madison.

—Charlie Daniel  
Diversity Coordinator

## What's in a name?

Just a reminder that the Alzheimer's & Dementia Alliance of Wisconsin was formerly the South Central Wisconsin Chapter of the Alzheimer's Association. We disaffiliated in December 2009 and are no longer part of that national organization. Today we are an independent, nonprofit agency dedicated to providing local services to people with dementia, their families and caregivers.

# Other news

## New Grant County evening support group

Take advantage of this time to meet with others who understand where you are coming from. This new support group meets on Wednesdays, April 27, July 27 and October 26, 2011 from 6:00 - 7:00 p.m. at Park Place, Community Room, 1075 N. Elm St., Platteville. Call Becky DeBuhr at 608.723.4288 for more information.

## "Food for the Soul"

The Dane County Caregiver Alliance is presenting their Ninth Annual Luncheon Program for Family Caregivers on Friday, April 15, 2011, 10:45 a.m. - 2:00 p.m. at Nakoma Golf Club, 4145 Country Club Road, Madison. Visit resource tables from 10:45 to 11:30 a.m. Dining room seating will begin at 11:30 a.m. The luncheon will feature The Unkalung Choir, a unique instrumental and tranquil choral experience.

Cost is \$12. Your RSVP is needed by Friday, April 8. We cannot accept payment at the door. Contact Attic Angel Association: 608.662.8900.

The Area Agency on Aging can provide referrals to respite providers. Contact Claire Culbertson: 608.261.5679 or culbertson@countyofdane.com.

## New geriatric assessment center in Reedsburg

The new Reedsburg Area Geriatric Assessment Center has opened at the Reedsburg Area Senior Life Center, 2350 North Dewey Av., Reedsburg. It is available one day a month. Robert P. Smith, M.D. is the Center's director. He is also director of the Richland

Area Geriatric Assessment Clinic and sees patients at the Richland Medical Center. To make an appointment, call 608.647.6161, ext. 4210.

## LEEPS program for those with memory loss offered

A new program called LEEPS (Language Enriched Exercise Plus Socialization) will be providing people with memory loss the opportunity for regular exercise and to become more active in their community. The program will use trained volunteers to assist with exercises, provide mental stimulation and offer regular outings. The program also allows the person's caregiver some respite time.

To be eligible to participate, you must have memory loss issues, live with your caregiver, be able to engage in exercise, and reside in Crawford, Grant, Green, Iowa, Juneau, Lafayette, Richland, Rock or Sauk counties. For information on the program or on becoming a volunteer, contact the Aging and Disability Resource Center of Southwest Wisconsin at 877.794.2372 (Rock county residents call the Alzheimer's Support Center, 608.314.8500).

## Family caregiver scholarships available for conference

A limited number of scholarships are available for the Wisconsin Network Conference on Alzheimer's Disease, May 1-3 at the Kalahari Resort in Wisconsin Dells. For information, contact Julie St. Pierre at 715.362.7779 or julie.stpierre@alz.org.

## Be a savvy donor!

Unless you see the Alzheimer's & Dementia Alliance of Wisconsin's name and logo with donations being sent to Madison, Wisconsin, your donation is **NOT** going to the Alzheimer's & Dementia Alliance.



Every dollar we raise stays in Wisconsin. We **ARE NOT AFFILIATED** with any of the following organizations you might be solicited from:

- Alzheimer's Association
- Alzheimer's Society
- American Health Assistance Foundation
- Alzheimer's Disease Research
- National Alzheimer's Coordinating Center
- Leeza's Place

Questions: 608.232.3400 or 888.308.6251.



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**RUTH IRENE PRICE**  
Kay Carter Heath

Shelley & Michael Muranyi  
**GERTRUDE REWOLINSKI**  
Linda Baumgartner  
**EILEEN RICCIO**  
Dana Palermo  
**PETER RIPP**  
Baker Tilly  
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Donna & Ed Hobbs  
Connie & Tom McKearn  
Evelyn Saemann  
Kathy Saemann  
Everett Scarborough  
**ROBERT SATHER**  
Lisa Friedrich  
**ALVIN SAUCIER**  
Shirley & Ted Hasenbeck  
**ARDYS SCHMELING**  
Brenda Swain  
**NANCY SCHROEDER**  
Lorna & Leo Sebald  
**MILDRED M SHULTIS**  
Terri Corwith  
Gloria & Phil Cracker  
Kay & Dave Daley  
Betsy DeMerit  
Mary Dickeman  
Dave, Theresa, Matthew & Melissa Dietz  
Barb & Ron Flick  
Mickey Garvey  
Jeanette Kelley  
Pat & Clarence Lee  
Bernice Matyas  
Donna & Paul Montgomery  
Ron Phillips  
Alice Retzlaff  
Karen & Jim Schiefelbein  
James Shultis  
Norene & Andy Shultis  
Marie Steinhorst  
Mary Vergara  
Shirley Vogel  
Ruth Walsh  
Ann & Richard Wiedenfeld

## Tributes and memorials Nov. 18, 2010 to Feb. 18, 2011

### In honor of:

**LINDA SCHOENMANN**  
Wilbur Lankford  
**JOYCE WEIGEL**  
Jerilyn Alsum

Manz Sunshine Fund  
Satyanath & Cheryl Menon  
Jackie Nielsen  
Louise & Charles Price

### In memory of:

**BERNADINE ADAMCZAK**  
Nathan Lange  
**LOUISE ALLEN**  
Martin Johnson  
**MAXINE BENELL SWEENEY**  
Isabel & Paul Benell  
City of Madison Fleet Service  
Jacqueline Dolph  
Cheri Matthews  
Sue McGuigan  
Diane & Scott Moll  
Ann M. Stone  
Lynn & Stuart Thomas  
Donna Thum  
Donald Wilson  
**PAT BUCKINGHAM**  
JoAnne & Myron Anderson  
Anna Marie Hallada

Pamela & Robin Reily  
**DELBERT BURNS**  
Patricia & Raouf Hanna  
**GORDON CORRIS**  
Priscilla Lietz  
**HILTON G DANIELSON**  
Maria Halper  
**LORRAINE DANIELSON**  
Maria Halper  
**MARY JANE DAY**  
A Bachner  
**PHILLIP FLYNN**  
Spring Harbor Middle School  
**FORMEMORY INC**  
Mary Kay Baum  
**VIRGINIA FRITSCH**  
Barbara & David Carlson  
Helen & Richard Dignan  
Elaine & Bob Fletcher

Williams Bay School District

**BERNARD STEINHOFF**

Jean & Thomas Flesch

Joseph Laeser

Joleen Sheil

Judith & Carlyle Whipple

**JOHN STEPANIK**

Nancy & Thomas Hoerter

**ORDEAN TORSTENSON**

Sylvia & Robert Torstenson

**MILDRED VICK**

Kathy & Phil Behrend

Karen & Donald Nihles

Alice Nordeng

Ruth Ann Reed

Patricia Schulz

Debra & Steven Seeliger

**MARYON WAND**

Anita & James Huffman

**DAVID ZANONI**

Barbara Zanoni

**In-kind donations**

**Nov. 18, 2010 to Feb. 18, 2011**

Barbara Lawrence

*Correction: Under "Contributions" for 8/1/10 - 11/17/10, the listing should have read:*

Laura Whitney

Aurora Williamson

*Please contact the Alliance office at 608.232.3400 to make any additions or corrections to this listing. We are deeply grateful to everyone who has supported the programs and services of the ADAW.*



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## Giving in uncertain times

As a donor, you want to do what's best for the Alzheimer and Dementia Alliance of Wisconsin, but economic news is poor and only slowly getting better. In uncertain times, how do you maximize what you can do to support the Alzheimer's Alliance? Here are some strategies:



**Stock gifts:** The market has rebounded to some extent. Now is the time to look at your portfolio of long-term, publicly traded stocks or mutual fund shares to see what might have increased in value and transfer shares to the Alzheimer's Alliance. You will realize tax savings by avoiding capital gains and you won't disturb the balances in your more liquid accounts. Your financial advisor can help you pick what is best for you and will help facilitate the transfer, not the sale, of the stocks.

**Life insurance:** If you have a policy on which you no longer pay premiums, you can name the Alzheimer's Alliance as the beneficiary and realize an immediate tax deduction in an amount equal to the policy's cash surrender value. If you are still paying premiums, you can irrevocably assign the policy to Alzheimer's Alliance who then becomes the beneficiary. Each year, you can make tax-deductible contributions to the Alliance equal to the policy's annual premium.

**Bequest:** An attorney friend of mine who believes in supporting charitable organizations asks his clients who are charitably inclined, "How much is enough to leave to your family? 95%? 90%?"

He suggests using the remaining percentage to support their charities as a legacy gift to the community. If you are still feeling uncertain about the future, you can always create what I call "if/then" statements. If you are married, nothing happens until you have both died and then the if/then statements are used.

For example, if the net value of your estate (after taxes and all other expenses) equals or exceeds "Value X," then gifts in the stated amounts should be made to your list of charitable organizations. If the net value of the estate doesn't equal "Value X," but still equals or exceeds lesser "Value Y," then gifts in lesser amounts will be made. If the value falls below "Value Y," then no gifts will be made at all. This type of planning assures that your family is provided for first and then your charitable interests. You could substitute a percentage for a fixed value, too.

Of course, you should discuss all gifts with your advisor whether that advisor is an attorney, financial planner, trust officer, or accountant. While advisors can't tell you what to do, they can provide an objective perspective on charitable giving, can discuss the tax considerations and provide advice on the best way to proceed according to your circumstances.

Finally, after you make provisions for the Alzheimer's Alliance, please notify the organization of your plans. I am always sad when someone provides a gift for my organization but doesn't tell me. Above all, it provides the Alliance an opportunity to thank you for your gift.

Even in uncertain economic times, there are ways to make sure that the future of the Alzheimer's & Dementia Alliance of Wisconsin is secure.

—Wendy Coe, Executive Director, American College of Veterinary Pathologists and Member, Legal & Financial Planning Committee

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For more information, including business sponsorship opportunities, contact Miriam Boegel or Kristin Larson at 608.232.3400 or 800.272.3900.

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