



be a part of finding a cure for alzheimer's

At the chapter, we often hear people say that they support the Alzheimer's Association because they want a cure for Alzheimer's to be found. Participating in a clinical trial is one of the most immediate ways you can make a difference, not only in your own life but in the lives of the millions who are affected or will become affected by Alzheimer's. The best part is whether you have Alzheimer's or not, you can participate in trials to help future generations overcome this disease.

Where Scientists Are Now

Over the last 15 years, scientists have made enormous strides in understanding how Alzheimer's disease affects the brain. Currently, the drugs available for the treatment of Alzheimer's only temporarily improve the symptoms of the disease; they do not stop the damage to brain cells that causes Alzheimer's to progress. But scientists believe that in the near future, therapies and treatments that slow or stop the progression of the disease will be available.

Ground-breaking research is going on that could have a measurable impact on the lives of current and future Alzheimer's patients. But a lack of volunteers for Alzheimer's clinical trials is significantly slowing down this research and the development of new Alzheimer's treatments. Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer's treatments.

Participating in a Clinical Trial

Without clinical trials, there can be no better treatments, no prevention and no cure for Alzheimer's disease. Scientists work constantly to find better ways to treat diseases, but improved treatments can never become a reality without testing in clinical trials with human volunteers.

Today, at least 50,000 volunteers, both with and without Alzheimer's disease, are urgently needed to participate in more than 100 actively enrolling clinical trials about Alzheimer's and related dementias.

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contact us

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why i ask

Leilani Pelletier, MS, Executive Director

The front door alarm beeps as someone walks in. The phone rings. The emails chime in. These are the sounds of an everyday business, but in our world, they are people with life changing and pressing concerns. And they don't know where else to turn.

As I watched 5 highly-qualified and skilled Care Consultants (it is so rare to have all five in the office at the same time) work with these families – each with a different story, each with a different need, all stemming from the same cause – I picked up the 6th call that came in for help at the same moment. The caller was in tears. She began telling me about her husband who was wandering away, and she couldn't keep him in the house. I did the best I could for her, we made a plan, and it worked for the most part when I checked on her the next week. But she was tired, and I could see she could not do this much longer without much more help. So we made a plan for that, too. For now it is working, and she is a little calmer.

She had planned to take him to the emergency room because she didn't know what to do anymore – didn't know how to manage his behavior and didn't know where to turn. She said she found out about us by mistake. She remembered seeing one of our purple Walk to End Alzheimer's Elephants somewhere, and thought there must be someplace to go for help. So she looked us up, and now she knows where to go. She wondered why no one pointed her to us in the past and told me she had felt alone for years. I told her that sometimes people don't want to seem like they are prying. She told me she wished someone who knew her husband had dementia had cared enough to pry. And my heart broke a little.

She is why I ask - why I ask you to volunteer, to donate, to sign up to be an advocate, to Walk, to run Marathons, to tell your doctor about us, to visit our website, and to refer someone to us. I ask because we work hard to be here for people just like her, and once they find us, things get a little better. Until we have done away with Alzheimer's and the related dementias, we will be here with that clear vision in sight. All we need is for you to see and do it with us.

please join us for our annual meeting

Thursday, November 17, 2011
6:30 – 8:30 pm

Chef's Restaurant

291 Seneca Street, Buffalo, NY 14204

Our annual meeting is open to the general public, and we invite everyone to attend to help celebrate the accomplishments of our volunteers and supporters. Please RSVP to the chapter by Thursday, November 10, 2011, by calling the chapter at 1.800.272.3900.

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be a part of finding a cure for alzheimer's

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So you're probably thinking, "Well, how do I go about finding a clinical trial?" The Alzheimer's Association has made this easy for you by developing TrialMatch™, a free service that makes it easy for people with Alzheimer's, caregivers, families, healthy volunteers and physicians to locate clinical trials based on personal criteria (diagnosis, stage of disease) and location.

TrialMatch is simple to use – with web and phone support, specially trained staff and tools developed with input from people with Alzheimer's. Since the service launched in July 2010, nearly 12,000 individuals have registered to search for Alzheimer's clinical trials. Currently, Alzheimer's Association TrialMatch lists 131 research studies with 545 trial sites nationwide.

The strength of this Web- and national 800 line-based service is its comprehensive, constantly updated database of Alzheimer's, mild cognitive impairment and other dementia trials taking place across the U.S. Specialists at the Alzheimer's Association's national Helpline – available

alzheimer's  association
trialmatch

24-hours a day – assist in the process of matching individuals to clinical trials for which they are eligible based on study criteria, diagnosis, treatment history and location. They answer questions about the trial process and connect individuals with trial sites based on their unique profile. Patients and caregivers are encouraged to share their trial matches with their healthcare professionals to help decide whether a clinical trial is appropriate.

Help Move Our Cause Forward

There are certainly a lot of things to consider when thinking about enrolling in a clinical trial. Read more about clinical trial myths vs. facts on page 10 of this newsletter. Volunteering for an Alzheimer's clinical trial is the ultimate service to our community. Will you enroll in TrialMatch today?

how to use alzheimer's association trialmatch

STEP 1:

Access TrialMatch online at www.alz.org/TrialMatch or by calling 1.800.272.3900.

STEP 2:

Complete a brief questionnaire, either online or over the phone, to create a profile.

STEP 3:

Based on specified eligibility criteria (i.e., diagnosis, treatment history, location), the Alzheimer's Association will match your unique profile to its clinical trial database.

STEP 4:

With your permission, an Alzheimer's Association specialist will contact you to provide unbiased trial result options and trial site contact information. Specialists will not recommend any particular trial, but will help you identify trials that match your specific eligibility and criteria. Alzheimer's Association TrialMatch specialists are available from 8 a.m. to 8 p.m., Monday through Friday.



dear helpline,

I noticed you have a group respite program but you only hold the program in Amherst and Williamsville. Are you going to be expanding your locations?

- Nancy, Hamburg

Nancy, I'm really glad you asked this question because we do plan on adding more social group respite locations over the next year. It has taken a lot of careful planning to put together a group respite model and refine it to where it meets the needs of our chapter, the respite participants, the location and volunteers who are hosting the respite. Now that our model is finalized, we do plan on reaching out to more community locations throughout the eight counties of Western New York to host a respite session.

I ask that if anyone knows of a location such as a community center or a place of worship that you think would be a great fit for a group respite location, please call our chapter. We will be looking at the hosting location to provide us with a pool of volunteers we can train for free to run the program. Most social group programs are only run once a month for a few hours, so the time commitment is minimal, but the service that is provided is priceless to the person with dementia and their caregiver.



*Kathleen Baumet, MSW
Director of Respite Services*

To find out more about our current group respite offerings, turn to page 9.

research highlights

From AAIC 2011

The Alzheimer's Association International Conference (AAIC) is the world's largest conference of its kind, bringing together researchers from around the world to report and discuss groundbreaking research and information on the cause, diagnosis, treatment and prevention of Alzheimer's disease and related disorders. This past July, more than 5,000 scientists from around the world gathered in Paris to report the latest advances in Alzheimer's research. Below you can read a little about three of the many studies presented at this year's conference.

- Scientists... reported on a study suggesting that falls are more common among individuals with the earliest brain changes of Alzheimer's. They measured the rate of falls among seemingly cognitively healthy older adults with and without preclinical Alzheimer's... Those people with amyloid deposits had twice the risk of falls. These study results suggest that, in some people, changes in gait and balance may appear as early indicators of Alzheimer's, even before memory changes.
- Researchers found that the width of certain blood vessels in the back of the eye were significantly different for people with Alzheimer's compared with healthy people... While most Alzheimer's-related pathology occurs in the brain, the disease has also been reported to create changes in the eye, which is closely connected to the brain and more easily accessible for examination in a doctor's office. The study is very preliminary, but encouraging.
- Results of a survey of people in France, Germany, Poland, Spain and the U.S. reported that while people fear Alzheimer's second only to cancer, the overwhelming majority say they would go to the doctor if they saw symptoms of memory loss and confusion. However, many of the respondents believe there is now an effective medical treatment to slow the progression of Alzheimer's; and many also said there is a reliable test currently available to determine if a person is in the early stages of Alzheimer's. Neither of these statements are true. The scientists say better public education about Alzheimer's is needed.

For details on the studies presented at the 2011 AAIC, visit www.alz.org/AAIC.

become an alzheimer's advocate

Alzheimer's advocates play an important role in improving the quality of care and quality of life for people with Alzheimer's disease and their families by working to improve dementia care and services; improve access to community-based care; improve quality care in residential settings; and expand funding for research and public programs serving people with dementia. As an advocate, you will:

- Receive regular updates about current legislative and public policy issues.
- Stay on top of policy and legislative issues through alerts and updates.
- Make calls or write to legislators to forward public policy priorities to improve quality of life for those living with Alzheimer's.

To become an Alzheimer's advocate, visit www.alz.kintera.org/wny/advocate.

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power your memory

lifestyle-based risk factors

Does Reducing Them Prevent Alzheimer's?

Previous research has identified a number of potentially modifiable risk factors for Alzheimer's disease. However, it remains unclear whether changing these mostly lifestyle-based risk factors would result in fewer cases of Alzheimer's.

At the Alzheimer's Association International Conference 2011, researchers presented a new mathematical model of global Alzheimer's risk suggesting that reducing the prevalence of well-known, lifestyle-based, chronic disease risk factors by 25 percent could potentially prevent 3 million cases of Alzheimer's worldwide, including nearly one-half million in the United States.

Scientists used mathematical modeling to calculate the percentage of Alzheimer's cases that may be attributable to diabetes, mid-life hypertension, mid-life obesity, smoking,



depression, low educational attainment and physical inactivity. The researchers caution that these estimates make an assumption that has not yet been proven – that there is a causal relationship between the risk factors examined and Alzheimer's disease, and that modifying the risk factors may lower Alzheimer's risk.

For more brain health information, attend or host a PowerYour Memory session. To schedule a Power Your Memory session for a group, call the chapter or to attend a pre-scheduled session, find out the details on the education calendar on pages 6 and 7.

ask the expert

Caregiver Emotions

*Michael J. Poulin, PhD
Assistant Professor,
University at Buffalo
Psychology Department*



Q: Does a helping hand mean a heavy heart?

A: It's certainly true that being a caregiver for an ill or disabled loved one can take a toll, physically and emotionally. However, some aspects of caregiving may actually be uplifting to caregivers.

Inspired by research that suggests that helping others increases happiness, my colleagues and I asked 73 spouse caregivers to keep careful track of how much time they spent each day actively helping their disabled spouse versus how much time they spent passively "on call." It turned out that caregivers' happiness increased the more time they spent engaged in active helping, even for seemingly unpleasant tasks like helping their spouse use the bathroom. This effect was strongest among caregivers who reported feeling strongly like they needed their spouse as much as their spouse needed them.

In short, helping can lead to happiness, even amid the trials of being a caregiver.



education calendar autumn 2011

Please Note:

All meetings are subject to change. Please call the chapter at 716.626.0600 or 1.800.272.3900 for more information and to reserve a seat.

The Western New York Chapter Office is located at 2805 Wehrle Drive, Suite 6 in Williamsville.



upcoming chapter events

September 17

Batavia & Medina Walk to End Alzheimer's

September 21

Alzheimer's Action Day (Go Purple!)

September 24

Buffalo Walk to End Alzheimer's

October 1

Chautauqua & Lewiston Walk to End Alzheimer's

November

National Alzheimer's Disease Awareness Month

November 3

Allegany County Dementia Care Conference

November 17

Annual Meeting

LEGEND

For Family Caregivers

For Healthcare Professionals

Open to the Public

For the Person with Dementia
and their Caregivers

October 4, 2011

Working as a Team: Relationships between Staff and Families

10:30 a.m. – 12 p.m.

Jamestown Community College –
Cattaraugus Campus
260 North Union Rd., Olean, NY 14760
Cost: \$29

*Note: Register by calling 716.376.7572,
and CEUs are available*

When it's not Alzheimer's: Exploring Other Major Causes of Dementia

1 – 2:30 p.m.

Jamestown Community College –
Cattaraugus Campus
260 North Union Rd., Olean, NY 14760
Cost: \$29

*Note: Register by calling 716.376.7572,
and CEUs are available*

October 11, 2011

Power Your Memory: Introduction to Memory Wellness

6 – 7:30 p.m., Chapter office

Cost: \$10

October 12, 2011

Memory Loss, Dementia, and Alzheimer's Disease: The Basics

12 – 1:30 p.m., Chapter office

Cost: Free

October 18, 2011

Know the 10 Signs: Early Detection Matters

6 – 8 p.m., Chapter office

Cost: Free

October 19, 2011

The Stages of Alzheimer's Disease

10:30 a.m. – 12 p.m.

Jamestown Community College –
Jamestown Campus
Carnahan Building, Continuing
Education, Jamestown, NY 14702
Cost: \$29

*Note: Register by calling 716.338.1005,
and CEUs are available*

October 20, 2011

Improving Daily Hands-On Care

10:30 a.m. – 12 p.m.

Jamestown Community College –
Jamestown Campus
Carnahan Building, Continuing
Education, Jamestown, NY 14702

Cost: \$29

*Note: Register by calling 716.338.1005,
and CEUs are available*

October 25, 2011

Managing Mealtime and Nutrition in Dementia Care

10:30 a.m. – 12 p.m.

Jamestown Community College –
Cattaraugus Campus
260 North Union Rd., Olean, NY 14760
Cost: \$29

*Note: Register by calling 716.376.7572,
and CEUs are available*

Positive Approaches in Dementia Care

1 – 2:30 p.m.

Jamestown Community College –
Cattaraugus Campus
260 North Union Rd., Olean, NY 14760
Cost: \$29

*Note: Register by calling 716.376.7572,
and CEUs are available*

Asset Protection and Medicaid Planning

6 – 7:30 p.m., Chapter office

Cost: \$5

*Guest Presenter: Judy N. Cuzzacrea
Wagner, Esq. Partner HARRIS BEACH
PLLC*

October 26, 2011

Enhancing Communication with a Loved One with Dementia

6 – 8 p.m., Chapter office

Cost: Free

October 28, 2011

Train the Trainer: Enriching Activities in Dementia Care

9 a.m. – 12 p.m., Chapter office

Cost: \$90

Train the Trainer Elective – Music and Alzheimer's: Making the Connection

1 – 4 p.m., Chapter office

Cost: \$90

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new volunteer opportunities

The chapter has designed a new volunteer system for people who are interested in working with our program team in providing direct services to people affected by Alzheimer's and dementia, caregivers, the general public and healthcare professionals. The system begins with general education and then moves to more specific training based on what programs and services volunteers would like to assist with.

To find out more about this new volunteer system, turn to page 8.

Each program volunteer must complete both part 1 and 2 of the Volunteer Essential classes. All education and training is free, and all sessions are held at the chapter office located at 2805 Wehrle Drive, Suite 6 in Williamsville. Please RSVP in advance by calling the chapter office.

Volunteer Essentials Part 1

October 6, 2011 | 1 – 4 p.m.

October 17, 2011 | 9 a.m. – 12 p.m.

November 2, 2011 | 5:30 – 8:30 p.m.

November 19, 2011 | 9 a.m. – 12 p.m.

December 2, 2011 | 1 – 4 p.m.

December 12, 2011 | 9 a.m. – 12 p.m.

Volunteer Essentials Part 2

October 13, 2011 | 1 – 4 p.m.

October 24, 2011 | 9 a.m. – 12 p.m.

November 9, 2011 | 5:30 – 8:30 p.m.

November 19, 2011 | 1 – 4 p.m.

December 9, 2011 | 1 – 4 p.m.

December 19, 2011 | 9 a.m. – 12 p.m.

Quarterly Volunteer Training Opportunity

Working with Caregivers and the Concerns they Face

December 13, 2011 | 6 – 7:30 p.m.

November 3, 2011

Allegany County Dementia Care Conference

3 – 8 p.m.

Crossroads Conference Center, 6087 State Route 19N, Belmont, NY

Cost: \$10

Note: Register by calling the chapter

November 9, 2011

Managing the Behavioral Symptoms of Dementia

12 – 1:30 p.m., Chapter office

Cost: Free

November 10, 2011

For the Person with Dementia

2:30 – 4 p.m., Chapter office

Cost: Free

November 15, 2011

Memory Loss, Dementia, and Alzheimer's Disease: The Basics

12 – 1:30 p.m., Chapter office

Cost: Free

Power Your Memory: What Research Suggests

6 – 7:30 p.m., Chapter office

Cost: \$10

November 16, 2011

Dementia Sensitivity for Families

6 – 8 p.m., Chapter office

Cost: \$15

November 18, 2011

Train the Trainer: Enhancing Communication in Dementia Care

9 a.m. – 12 p.m., Chapter office

Cost: \$90

Train the Trainer Elective: Managing Mealtime and Nutrition in Dementia Care

1 – 4 p.m., Chapter office

Cost: \$90

December 7, 2011

Caring for Someone with Dementia during the Holiday Season

12 – 1:30 p.m. OR 6 – 7:30 p.m.

Chapter office

Cost: Free

December 13, 2011

Power Your Memory: Anatomy of a Memory

12 – 1:30 p.m., Chapter office

Cost: \$10

December 16, 2011

Train the Trainer: Late Stage Dementia Care

9 a.m. – 4 p.m., Chapter office

Cost: \$90



new volunteer opportunity

What do health fairs, respite, and support groups all have in common? Besides being wonderful services offered by our chapter, they are all fueled by volunteers. Without our amazing volunteers, we would not be able to serve our community as well as we do. But we want to help more people. Would you like to help?

New to our education calendar are free, six-hour trainings for new or potential volunteers, which will be offered nearly twice a month at our chapter. These trainings will give volunteers the basic foundation they need before going on to more specialized training to learn how to help us provide services like respite or even take Helpline phone calls.

“Not having a background of personal experience, I found the training was a very helpful introduction and has inspired me on to reading books from the chapter’s library in order to find out more details,” says Trevor W., one of our new program volunteers. “It was very helpful for me to hear people who were dealing with Alzheimer’s disease speak about personal experiences.”

These trainings are not required of all volunteers, just those who wish to help in certain areas. However, if you are a current volunteer or you are just thinking about volunteering with us, you are welcome to attend these sessions. For more information about volunteer opportunities or to find out whether you would need to go through one of these trainings, contact our volunteer coordinator (volunteer.coordinator@alz.org), visit our website, or talk to any member of our staff.

“[The training] was really great. We were able to perceive how someone with Alzheimer’s might feel when going through their daily tasks and understand what they feel like in a direct way. That was my favorite part, to really empathize with them,” explained Brittany H. who is a program volunteer who recently attended the Volunteer Essential classes.

Interested in attending, but our chapter office is too far away? Like all of our other educational programs, we’ll take this training to you, too! All you have to do is contact us. For those of you willing to come to our office for the training, **please turn to page 7 to view all of our upcoming Volunteer Essential classes.**

Are you a current support group, respite, education, early stage, or Helpline volunteer? We ask that all volunteers in these areas attend at least one educational opportunity each year. In an effort to make this easier for our volunteers, we are now offering an additional volunteer training quarterly at our chapter office. The goal is to help learn new skills, help our volunteers meet and connect with one another, and share ideas or concerns. Topics will change each quarter and suggestions are welcome. See what our additional volunteer opportunity is this quarter on the bottom corner of page 7.

Chapter Support Group Locations

We hold over 30 support groups throughout WNY. Support group dates, times and locations are frequently changing, so we are only including locations where we currently hold support groups. Please visit www.alz.org/wny or call the chapter for a complete list of our support groups.

Specialized Support Groups

- Daughters Only (Williamsville)
- Early Stage (Williamsville)
- Early Stage Couples (West Seneca)
- Caring for a Loved One in a Facility (N. Tonawanda)
- Middle Stage Couples (Williamsville)
- Wives Only (Williamsville)
- Men Only (Williamsville)

Additional Support Group Locations

- Batavia
- Belmont
- Buffalo
- Cheektowaga/ Depew
- Clarence
- Getzville
- Hamburg
- Jamestown
- Kenmore
- Lewiston
- Lockport
- Machias
- Medina
- Newfane
- North Collins
- North Tonawanda
- Olean
- Orchard Park
- Williamsville



From left to right, Todd Benzin, Peter Cumbo, Don Gervasi, John Kreuzer of the Eclectic Improv.

early stage group learns a new exercise for the mind: improv

There's a saying that laughter is the best medicine, something our early stage participants have been exploring through improvisational comedy with Eclectic Improv. Improv is a creative exercise for the brain, which sharpens wit while the person is having fun. The fun comes from the spontaneity, and sometimes silliness, that emerges during an exercise.

In addition to the laughter that comes from these exercises, improv is healthy for the brain as well. Don Gervasi of Eclectic Improv explains, "...our brains do what they can to make connections. Our exercises and games can help that process along by presenting the individual with a variety of fun and new thinking about their environment and their ideas. In improv there is no wrong answer; in fact, improvisers try to make everyone's idea the right one."

There are groups nationwide currently researching how improvisational comedy and other creative arts might help those in the early to middle stages of Alzheimer's cope with their disease. According to researchers, not having to memorize lines or remember a story narrative might spur confidence by freeing the person from worry over lost words or thoughts, and actually stimulate their brain to forge new pathways. Because there are no wrong answers, the group can follow the lead of each participant creating silly outcomes in which everyone can feel they contributed to the story and laughter.

Eclectic Improv met with our early stage group this summer to lead a few workshops. During these workshops we played games like "Pass the Clap," a rhythmic exercise, and "Tiger, Martian, Salesman," a spin off of "Rock, Paper, Scissors" with the changed goal of getting the entire group to be the same character. Another exercise titled "What's in the Box?" challenged participants to look inside their imaginary box and tell us all of the items in that box they could "see." These exercises emphasized coordination, rhythm and spontaneity and allowed the group to have fun together in a warm, accepting environment.

Eclectic Improv and the chapter hope to partner for another round of improv sessions in the future. If you would like to be notified of when the next improv sessions will be held, call the chapter or e-mail program.wny@alz.org.

wyoming county support

The chapter would like to begin a support group in Wyoming County for caregivers caring for someone with dementia. If you would either like to lead this group as a support group facilitator or attend this group as a participant, please contact the chapter office at 1.800.272.3900.

social respite groups

Our social group respite programs allow a person with dementia to exercise their independence and connect with new friends while participating in group activities. It also gives their caregiver some free time to meet with friends, go shopping or do things around the house.

Social Respite Group Schedule

First Tuesday of the month

5:30 – 8:00 p.m. | Held in Williamsville

Third Saturday of the month

11:00 a.m. – 2:30 p.m. | Held in Amherst

All participants of our social respite program must first be assessed by a chapter staff member before joining the group. Once individuals are accepted into the program, the exact locations of the groups will be disclosed. If you would like to learn more about our respite programming, call the chapter at 1.800.272.3900.

thank you volunteers!

We wanted to send a special thank you to all of the volunteers who worked at the Taste of Buffalo and Buffalo Wing Festival on behalf of the Alzheimer's Association. You are a crucial part of our organization, and your participation is helping to move our cause forward.

clinical trial myths vs. facts

To find out more about clinical trials, read the cover story on page 1.

Myth: It's too late – the disease is too advanced to participate in a research study.

Fact: There are clinical studies that work with people in every stage of Alzheimer's. Participating in a trial could have a potentially measurable impact on the disease.

Myth: If I join a clinical trial, I won't receive the same quality of care that I currently have with my doctor.

Fact: Participants in clinical trials receive a high standard of care. All participants have the opportunity to talk with study staff, and should also continue care with their doctors.

Research shows that people involved in clinical studies do somewhat better than people in a similar stage of their disease who are not enrolled, regardless of whether the experimental treatment works. This may be due to the general high quality of care provided during clinical studies.

Myth: It costs too much to participate in a clinical trial.

Fact: Every clinical trial is designed differently. Some clinical trials reimburse associated travel costs, and some may provide compensation to participants. Still, there may be costs associated with participating, so contact your trial site for information pertaining to a particular trial of interest.

Myth: If there is a clinical trial that could help me, my doctor will tell me about it.

Fact: More than 100 Alzheimer's clinical studies are currently taking place. Your physician may be unaware of all the research studies in your area. For the most up-to-date information about clinical trials in Alzheimer's disease, visit Alzheimer's Association TrialMatch at www.alz.org/TrialMatch or call 1.800.272.3900.

professional caregiving tips for the holidays

Holidays, while a lot of fun, can also be a lot of work in a long-term dementia care setting. Here are some tips to help each holiday, from Halloween to New Year's Day, go more smoothly:

- Try to maintain a routine as close as possible to normal.
- If family members are planning on taking their loved ones out of the facility, encourage them to do a trial run before the holiday. Let families know that staff will be available should they need to bring their loved ones back earlier or later than planned. Pack enough supplies for family members to take for their loved ones while they will be out of the building.
- Host a holiday celebration, and be conscious of each individual's cultural preferences. If the holiday is religious in nature, offer opportunities for scripture and worship services.
- Celebrations earlier in the day may be better to avoid any potential sundowning in the afternoon or evening. Smaller gatherings can be more enjoyable, since noise and confusion are limited.
- Keep at least one area of the facility a quiet area to which individuals can retreat if needed.
- If gifts are being given, keep wrappings simple. The purpose of gifts may need to be explained.
- Schedule some passive activities, especially music and reminiscing, which everyone can enjoy.
- Avoid excessive decorations which can disguise the environment and cause increased confusion.
- Have activities for visiting children on hand.
- Talk to staff about their role in relating and empathizing to family members. Often family from out of town will visit and might be surprised to see how much their loved one has changed since they last visited. These family members may need to talk to a staff member to understand dementia and how it progresses.
- Consider extra help from volunteers during holiday celebrations or on days leading up to celebrations. Volunteers can paint nails, help decorate, and spend time with residents who may not have family visiting. Also consider adding extra staff when it is known that many residents will need assistance getting ready to go out of the facility or when families will be visiting. This way, each individual can have more individualized staff attention to help them look their absolute best when celebrating.
- Finally, do not forget to do something extra special for your staff and co-workers.

dear readers

By Sarah Harlock, MBA, Director of Development

Thank you so very much for your continued confidence in and support of our work at the chapter. It has been a year of pressing and urgent need. The prevalence of Alzheimer's and related dementias is growing at an alarming rate worldwide.

At the national, state and local levels, people are starting to really live the impact of this disease and demand for our services is ever growing in number and complexity. We have responded to this increase in need by adding and enhancing programs as well as gaining additional volunteers and chapter staff. It is your generosity that allows us to continue to serve the Western New York community.

As you look to decide on a holiday gift for someone you love, or to make year-end or holiday contributions to charity, please consider donating to the Alzheimer's Association, Western New York Chapter. You can donate in honor or in memory of someone, and the person you designate will receive a letter from our Executive Director, Leilani Pelletier, notifying them of your gift. As always, you will receive a letter acknowledging your tax-deductible donation.

As you host your holiday get-togethers, try what others are starting to do, declining gifts and bottles of wine and offering the opportunity to donate to the chapter. A simple basket by the door will remind people on their way in or out.

Here are some examples of how we are meeting the new and increased need for local services:

- The demand for programs for individuals in the early stages of the disease has grown and as a result, we are preparing to expand the early stage program offerings outside the Buffalo area. This expansion requires time, meetings, research, training and ongoing chapter support.
- The Missing Vulnerable Adult Act, passed by New York State and signed by Governor Cuomo, came right from our advocacy work with the NYS Coalition of Alzheimer's Association chapters. It is a mighty step towards protecting individuals with memory-impairing illnesses who become lost. This new law ensures the Alzheimer's Association will be involved in training law enforcement officials and first responders.
- Another identified need is comprehensive, ongoing medical evaluation and treatment for individuals with memory loss. To this end, the chapter has initiated a project focusing on a new memory care center – with details to follow.
- Social group respite programs that allow care partners to leave their loved ones in a safe program for a few hours has also seen an increase in attendance. We have started work on opening more sites in Chautauqua and Erie counties.

Not to be forgotten is the fact that the Alzheimer's Association is the largest private funder of Alzheimer's research in the world. We are at the forefront of research; looking for better treatments and a cure. The Alzheimer's Association funds independent investigators worldwide through our International Research Grants Program. Since awarding our first grants in 1982, we have awarded in excess of \$279 million to more than 1,900 projects.

We are extremely grateful for the generosity of the Western New York community. It is you who allows us to continue to serve those in need throughout the eight counties of Western New York. Thank you for considering us as your charity of choice for holiday and year-end contributions.

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