Since awarding its first grants in 1982, the Alzheimer's Association has grown into the world's largest nonprofit funder of Alzheimer's research, awarding more than $300 million to over 2,100 best-of-field grant proposals.

One area in which we show our commitment is in the area of new investigators. We believe it is important to attract the best and brightest young researchers to the area of Alzheimer's research. These grants advance research while supporting the early-career development of researchers who earned their doctoral degrees within the last 10 years. We are pleased to announce that once again a young researcher in West Virginia was awarded one of the Alzheimer's Association New Investigator Grants - Dr. Miranda Reed, Associate Professor of Psychology at West Virginia University. Dr. Reed follows Dr. Justin Legleiter, Associate Professor of Chemistry who was awarded a two year grant in 2011.

Miranda, first tell us how you came to WVU?

I came to WVU in 2010. The Psychology Department had just started a new program called Behavioral Neuroscience and were searching for the first official hire. I was drawn to the program because my work examines the molecular basis for memory loss in Alzheimer's disease and frontotemporal dementia, and has both a neuroscience and behavioral component. I also very much liked the idea of helping to develop a new program.

What led you to begin research on Alzheimer's disease?

My Ph.D. work focused on how early life exposure to toxicants, such as mercury or lead, accelerate the aging process. The aging portion of my dissertation research greatly interested me and I wanted to continue that line of research. When looking for postdoctoral positions after finishing my PhD, I focused on Alzheimer's disease given that the greatest risk factor is aging. I also felt that losing one's memory had to be one of the worst disease symptoms I could imagine and wanted to contribute to the prevention of this disease.

Why did you decide to focus on the diabetes connection?

Diabetes is both a risk factor for Alzheimer's disease, as well as a comorbidity. That is, diabetes increases one's risk for Alzheimer's disease and many individuals with Alzheimer's disease also have diabetes. I wanted to determine how diabetes alters the risk for Alzheimer's disease and also whether having both diseases altered the brain in ways that differed from having only one of the diseases. The latter could be important for drug development. If Alzheimer's therapies are initially tested in mouse models and humans with only Alzheimer's disease, the drug's effects may differ when applied to individuals with both diabetes and Alzheimer's disease. My lab will test this hypothesis.

Explain your research project in layman's terms for us.

We will induce diabetes in a mouse model of Alzheimer's disease in one group of mice when they are young and in another group of mice when they are old and will answer the following questions. First, does diabetes worsen the memory deficits of Alzheimer's mice? Second, does diabetes accelerate Alzheimer's pathology in the brain? Third, does the brain of a diabetic, Alzheimer's mouse differ from the brain of a mouse having only Alzheimer's or diabetes? Fourth, does Alzheimer's disease in an aged mouse differ from Alzheimer's disease in a young mouse? Fifth, does aging alter the effects of diabetes in Alzheimer's mice? Essentially, we want to know how the aging process and diabetes alter Alzheimer's disease?

I know you were able to attend the Alzheimer's Association International Conference this July in Vancouver. Tell us about your experience there.

This was an excellent conference because it focused only on Alzheimer's disease and related dementias and many of the best researchers in the field were there. The ideas and findings that are presented usually will not be published for another six to twelve months.

Dr. Reed, continued on page 14
From the Executive Director

I recently had an interesting encounter with one of the residents at the assisted living where my mother resides. “Sally” has dementia and is one of the more “challenging” residents. She rarely stays in her room and greets everyone-staff and visitors alike- with her two favorite questions… “Are you ok?” or “Where am I going?” And she expects an answer!

As I was coming off the elevator from the second floor, reading an email on my Blackberry, I saw Sally out of the corner of my eye…but I was preoccupied so I did not look up and say, “Hello” as I usually do. As I walked past her toward the exit I heard her ask the usual question, “Are you ok?” and I answered, “Yes, I’m ok, Sally, are you?” but I did not look up and kept walking. I heard her murmur, “I don’t know. Am I ok?” I intended to answer, but I was still reading my email so I was a bit slow with my response. She said again, louder, “Am I ok?” And then she caught up with me, grabbed my arm and with a panicked look on her face said even more loudly, “AM I OK?” I quickly patted her arm, looked into her eyes and said, “Yes, Sally, you are ok. You are just fine.” She looked very relieved and said, “Thank you” and walked away.

We all just want to know we are ok. I am revealing my age when I refer to the well known book from back in the 70’s I’m Ok, You’re Ok that remains one of the best selling self-help books of all time. But it seems to represent a very basic need for all of us. The person who is experiencing changes, memory loss, and is worried about what is happening, just wants to know she is ok. The caregiver who feels flustered, rushed and worried that he is not doing a good job, just wants to know he is ok. And the same goes for you and me.

And that is what we at the Alzheimer’s Association hope to achieve. Unfortunately, being ok, at this time, does not mean you are disease free. It does not mean your caregiving duties are taken away. But it does mean someone cares. It means you have an outlet for your fears and frustration. You have a source for advice, resources and reassurance. You have an advocate who is going to battle for you with Congress, the legislature and the healthcare system. And you can rest assured that someone is trying to find the ultimate “ok” for you…..effective treatments and a cure. We are doing our very best to ensure that someday being, “OK” will mean a world without Alzheimer’s.

We hope this newsletter brings you helpful information, especially during the upcoming hectic holiday season- when it is important that you take care of yourself, so you can be “ok.” Call us if you need us. And please know that your Walk contributions, your end of year donations, memorial designations and your loyal support are appreciated and used with the utmost efficiency and care. Your generosity helps our organization be “OK.”

We at the Alzheimer’s Association, West Virginia Chapter wish you an “OK” Holiday season and a very “OK” New Year.

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Walk to End Alzheimer's

GRAND TOTAL
$297,897

Mid-Ohio Valley

Total participants: 505
Total raised: $43,015

Bluefield-Princeton

Total participants: 230
Total raised: $145,463

Western Greenbrier Valley

Total participants: 329
Total raised: $30,015

Eastern Panhandle

Total participants: 329
Total raised: $30,015

Charleston

Total participants: 1,100
Total raised: $124,579

Huntington

Total participants: 145
Total raised: $21,715

Buckley-Oak Hill

Total participants: 270
Total raised: $30,605

Total raised: $9,000
Walk to End Alzheimer’s

THANK YOU WALK SPONSORS!

Thank you to all of our fall Walk to End Alzheimer’s sponsors. Without the generosity and support of these companies, organizations, and individuals, our Walks would not be as successful or enjoyable. Thank you, Sponsors!

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Investing in the Mission

Most of us go about our daily lives with the expectation that our hard work and proper planning will pay off in the future. Much like corporate America, society measures success in terms of growth, profit, loss and dividends – a positive return on investment.

The Alzheimer’s Association views your charitable contributions in similar fashion, as a financial investment in our mission. Much like a Fortune 500 Company, the Alzheimer’s Association, West Virginia Chapter is committed to providing, “maximum dividends” for our “shareholders.” So, why should someone choose to invest in the Alzheimer’s Association?

GROWTH TO MEET NEEDS. While we know that our programs provide critical support to individuals and families who contact us every day, we also know there are millions more whom we have not yet reached. We continue to pursue our goals of growing concern and awareness and increasing care and support to reach them. Our collaboratively developed strategic plan emphasizes activities that grow our capacity to provide consistent, high quality programs and services across the country to more people each year.

GROWTH TO CHANGE SYSTEMS. Alzheimer’s Association’s advocates, through consistent and growing pressure on our elected officials were successful in 2011 with the passage of the first federal Alzheimer’s legislation - the National Alzheimer’s Project Act, (NAPA) which mandated a national plan to address Alzheimer’s. In the areas of research, provider education and caregiver support, the resulting National Alzheimer’s Plan set forth deliverable benchmarks by which success will be judged. The Association is committed to growing our advocate network and continuing our involvement with government leaders to ensure implementation and achievement of these goals.

DRIVING INNOVATION. Over the past six months, the Alzheimer’s Association announced multiple significant research initiatives including investing $4.2 million dollars in the Dominantly Inherited Alzheimer’s Network – Therapeutic Trials Unit, a global study to investigate Alzheimer’s caused by dominantly inherited genetic mutations. This innovative initiative will allow researchers to determine which therapies might have preventive effectives in those who have the inherited gene mutations, thus ultimately preventing onset of symptoms. These innovations – projects that would not have occurred without the Alzheimer’s Association – are fueled by donors like you who give so generously to help us change the course of this disease.

LEGACY FOR THE FUTURE. A primary objective among investors is to not only preserve wealth but also leave something for future generations. Without disease modifying discoveries, the cost to our government will be over $1 trillion dollars by 2050. However, if a treatment becomes available in the next few years, to slow the progression, it would save Medicare and Medicaid $20 billion dollars. Your gifts power the engines of discovery and intervention, driving our mission forward and bringing us closer to a world without Alzheimer’s disease.

INSTANT GRATIFICATION. Few investments can offer both long-term stability as well as immediate results. By investing in the Alzheimer’s Association you can INSTANTLY take comfort in the fact that those dollars are providing real, tangible support and assistance to families struggling to care for loved ones that are suffering from this insidious disease. We are committed to the people who need us NOW while ensuring a more positive future for our children and grandchildren.

Even given the serious reality of Alzheimer’s there has never been a more exciting time to be a part of the movement to end this disease. All around us are signs that our investment is paying off. With increased support from donors like you, we are able to make a difference now and change the course of this disease for future generations.

We truly appreciate your continued support and your investment in our vision…a world without Alzheimer’s.
Help During the Holiday: From One Caregiver to Another

by JT Hunter, Family Services Coordinator

As the holiday season is rapidly approaching, we tend to think this time of year is supposed to be a time of joy and happiness – family togetherness and gift giving. Sometimes, however, if you are a caregiver for an aging parent or a loved one with Alzheimer's or a related dementia, the holidays can be a time of overwhelming stress.

As a caregiver, the holiday season may mean having to perform all of your care giving duties, PLUS you feel the pressure to fulfill all the traditional holiday obligations. Caregivers often battle feelings of stress, guilt and anger, and those may increase with the holiday pressure. For both the caregiver and the person with Alzheimer's, the holidays can be reminders of “better times.” So once again, it’s no surprise that caregivers say they feel overwhelmed, out of control and out of patience during the holidays. They are!

Using tips from many of the caregivers I have come to know, plus experience learned as a caregiver, here are some suggestions to ease the pressure and hopefully make this holiday season a more joyful time of year for all.

**ADJUST & SET REALISTIC EXPECTATIONS**

Things will be different. Alzheimer's has entered your world and it does make some aspects of life different. The reality is that we can’t aim for perfection anymore. It is unrealistic from here on out. However, what we can do is be flexible, and when we need to, change our expectations to fit the situation. For example: a person with Alzheimer's often cannot tolerate as much stimulation as they once could. A typical holiday setting with all of the hustle and bustle can be overwhelming. AND it can be overwhelming for YOU now too! Give yourself permission to do only what you can reasonably manage. If you’ve always invited 15-20 people to your home, consider inviting five for a simple meal. Have a holiday lunch instead of a dinner. More suggestions include:

- **Timing is everything.** Have events earlier in the day to avoid evening confusion.
- **Consider having a potluck or asking others to host the holiday at their home.**
- **Plan time for breaks at holiday gatherings so your loved one can rest in a quiet area away from noise and crowds.**
- **Plan to serve easy to eat finger foods and lower music levels.**
- **Have a family meeting, conference or write a letter to friends and family that will be visiting or hosting over the holiday season. Discuss potential behaviors that the person may exhibit and how to address them.**
- **Discuss the holiday celebrations and traditions of years gone by and determine which of these to continue and what new traditions may be implemented.**
- **Make sure that everyone understands your caregiving situation and has realistic expectations about what you can and can’t do.**
- **Encourage people to buy useful gifts for your loved one: comfortable clothing, album of their favorite music, videos and photo albums. Helpful gift ideas and suggestions for persons with Alzheimer’s can be found at www.alz.org/wv as well as www.alzstore.com or you can contact your local Alzheimer’s Association for gift ideas and suggestions for a person with Alzheimer’s at 800.272.3900.**

**TAKE CARE OF YOURSELF**

You have the right to say no. It is not being selfish and you should not feel guilty. No one should expect you to maintain every holiday event or tradition but if they do you may need to say no to some things. And that is OK.

- **Find a de-stressing technique.** For some people it is exercising, for some it’s reading a good book, for others it’s humor. It can be anything you enjoy doing that takes your mind of the stress for a little while. Understand that even a few minutes of this de-stressing can have great effect on your health and stress levels.
- **Maintain your health.** If you don’t care for yourself you will not be able to care for anyone else. Don’t skip medications or medical appointments. Do your best to exercise and eat properly to help sustain your energy and try to avoid alcohol.
- **Put together a support network.** Make a list of family, friends, community agencies and local emergency service providers.
- **Make a holiday “To-do” list or calendar.** Figure out which activities you should do yourself and which ones you can delegate. Then get comfortable delegating!
- **Ask a friend or relative if they can provide specific help.** For example, “Can you please take John to his doctor’s appointment on Friday?” or, “Can you come over and watch Mary for three hours next Saturday while I go shopping?”
- **Prepare for post-holiday letdown after your family members have gone back home.** Arrange for in home care so that you can enjoy a movie or lunch with a friend and reduce some of the post-holiday loneliness you may feel.

Help during the Holidays, continued on page 14
Wandering is one of the most unsettling behaviors people with Alzheimer’s display. For what looks like unknown reasons, they develop a need to go out into unknown territory, or develop new patterns that put them at great risk for becoming lost. What is often labeled as aimless activity is often an attempt to communicate after language skills have been lost.

Alzheimer’s caregivers worry about the risk, but are often not ready to put safety measures in place that may mean the difference between a life and death situation, if the person does go missing. All too often we hear that the person with dementia, “isn’t that bad yet”; “Is not left alone”; “Never goes outdoors”; “Goes on walks around the neighborhood or on the property, but always comes back”. But we recommend “Never Say Never.”

Who is at risk of wandering?

Six in 10 people with dementia will wander.

Anyone who has memory problems and is able to walk is at risk for wandering. Even in the early stages of dementia, a person can become disoriented or confused for a period of time. It’s important to plan ahead for this type of situation. People with Alzheimer’s disease are being affected by a degenerative brain disease. They have changes occurring in their brains that will not just affect their memories, but their vision, perception, language, word finding and comprehension. It is not uncommon for people with Alzheimer’s type dementia to become disoriented or lost in their own home due to these changes. This is merely an aggravation when Grandpa cannot remember where his bedroom is. Once outside the home, the added distractions created by sights, sounds, smells and temperature can greatly decrease their ability to focus and accurately navigate. We have had conversations with caregivers, who have had loved ones walk outside, turn back to the house and not recognize the house, and were not able to identify how to go back into the home.

So what may contribute to the initial event?
A normal daily routine, like a walk or a drive to the grocery store. Something as simple as feeling lost, or as though they have lost something. Colors, sunlight, rain, wind, traffic patterns, noises, animals, voices, detours, can all contribute to altering the person’s perception as well as reflecting on a past experience or event that may create a need to seek or flee. It can also signal such basic needs as hunger and thirst, the need to void, or the need for exercise or rest. Wandering also may be related to:

• medication side effects,
• attempts to express emotions, such as fear, isolation, loneliness or loss,
• curiosity,
• restlessness or boredom,
• stimuli that trigger memories or routines, such as the sight of coats and boots next to a door, a signal that it’s time to go outdoors,
• being in a new situation or environment.

Make a plan. Explore home safety tips and safety support programs in your area. It’s important to plan ahead. Wandering among people with dementia is dangerous, but there are strategies and services to help prevent it. Suggestions include:

• Keep a current photo of the person with dementia, and update it at least monthly.
• Keep a journal of normal daily routines and patterns, AND note any changes in those patterns (changes you have created and changes you have experienced in the person’s communication, verbalizations, personality and needs).
• Document medical conditions or limitations the person has (like distance they are able to walk, visual impairment, hearing impairment).
• Maintain a list of favorites and a list of dislikes — update the list as changes occur
• Make a history of past life experiences that may have been life altering or memorable (things they spoke about both positive and negative).
• Alert neighbors and local law enforcement of your caregiving for a person with dementia so they can be aware, and attuned to anything out of the ordinary.
• Make sure the person with dementia has ID on them. Even a business size card in every pocket can be helpful. If your loved one is enrolled in Medic Alert® + Safe Return® you will receive not only ID cards but clothing tags as well.
• If the person with dementia goes missing, call 911 immediately. Time is precious for recovery, and there is no 24-hour missing persons waiting period for someone with Alzheimer’s or a dementia.
This past spring, the Alzheimer’s Association, West Virginia Chapter’s Caregiver University trained more than 250 family and professional caregivers. Workshops ranged from understanding legal and financial issues and Alzheimer’s disease to improving communication with a loved one with Alzheimer’s disease to using your VOICE to advocate for a world without Alzheimer’s. Thank you to the many sponsors, vendors and locations who made Caregiver University possible!

Caregiver University will return in the spring of 2013! Anticipated Caregiver University locations are:
- Wheeling
- Eastern Panhandle
- Huntington
- Charleston
- Morgantown
- Athens, OH

We are still in the planning phase, so if you would like to see Caregiver University come to a city or town near you or have a specific topic you would like for us to cover, contact us, at 800.272.3900!

For more information contact Jennifer Waggener at 800.272.3900 or jennifer.waggener@alz.org

The Gold Standard in Training

The Alzheimer’s Association, West Virginia Chapter continues to provide a variety of training topics to meet your staff’s dementia care needs. From improving communication to activities to working with families, each of our training topics is designed to improve your staff’s capacity for care.

Studies consistently show, organizations who invest in training experience less staff burnout and staff turnover. All aspects of our recommendations and our training programs are based on the best evidence available in effective dementia care. The Association provides cutting edge classroom training programs that provide and interactive, educational and fun experience. The Association’s training programs meet professional continuing education standards as well as trainings specifically designed to meet WV OHFLAC guidelines. Training packages are designed to be flexible to meet your busy schedule.

As you plan your staff’s continuing education this year, keep in mind families want the best for their loved ones, they want the gold standard. All topics are offered at $85 per hour, plus travel expenses.

- ADL Challenges of Personal Care
- Alzheimer’s Disease at the End: Late Stage Care
- Activities: Life from Dusk to Dawn and Beyond
- Developmental Disabilities & Alzheimer’s (2 hrs)
- Eating, Dining & Nutrition
- Effective Communication (2 hrs)
- Fall Prevention
- Alzheimer’s and Hospitalization: Chaos or Calm
- Sexuality, Intimacy & Alzheimer’s Disease
- The Problem of Pain & Dementia
- Non Verbal Communication
- Working With Families
- You Have the Right to Remain Silent (Residents’ Rights)
- Therapeutic Environmental Modifications
- Assessments and Careplans
- Understanding & Responding to Behaviors (2 hrs)
- Basics of Alzheimer’s Disease
- Alzheimer’s Disease: The Basics of Best Care, live (2 hrs)
- Alzheimer’s Disease: The Basics of Best Care, web
- Alzheimer’s Disease an Interdisciplinary Team Approach (2 hrs)
- Building a Good Alzheimer’s Team (2 hrs)
- Abuse Prevention
- Medication Management

SCHEDULE A COMMUNITY WORKSHOP

Basics of Alzheimer’s Caregiver Stress
Brain Health & Wellness
Partnering With Your Doctor

To schedule a workshop:
800.272.3900 • www.alz.org/wv
Dr. Dean Hartley Visits West Virginia

Dean M. Hartley, Ph.D., Director of Science Initiatives at the Alzheimer’s Association, visited West Virginia on November 9 for the Annual Jose Ricard Conference in Huntington to share the latest in Alzheimer’s research.

Dr. Hartley plays a key leadership role in effectively communicating the goals and achievements of the Alzheimer’s Association’s research and science program to a wide range of audiences. In addition, Dr. Hartley represents the Association’s science division, both internally and externally, and works with the division’s senior leaders on public relations activities and scientific workgroups to advance the Association’s science agenda.

Before coming to the Alzheimer’s Association, Dr. Hartley was an Associate Professor in the Department of Neurological Sciences and conducted research at Rush University Medical Center in Chicago. Prior to this, he was Assistant Professor in the Department of Neurology at Harvard Medical School and conducted research at Brigham and Women’s Hospital, Boston.

A significant portion of his research career has focused on abnormal protein folding and how this may initiate Alzheimer’s disease. In addition, he investigated how abnormal electrical activity may play a role in the progression of Alzheimer’s.

Welcome to WV Dr. Hartley! We are so pleased to have you with us in WV. How do you think the new TrialMatch® is going and what impact do you think it will have on research?

Clinical trials are a critical aspect of identifying effective treatments and preventions for Alzheimer’s disease. It is difficult to get individuals to enroll in trials these because of the lack of public information on the need for volunteers, as well as how to enroll in trials. TrialMatch can help expedite this process by providing free enrollment information. TrialMatch was started in 2010 and since then 661 individuals have joined. As more drugs enter clinical trials, TrialMatch will be of utmost importance not only in helping these clinical trials go forward, but helping to expedite critical step.

Some of us are very impatient and have to be reminded that things take time! How are we really doing in our progress in Alzheimer’s research?

From the public perception it seems we have not made any progress because we do not have any treatments to change the course of the disease and recent setbacks in clinical trials. Even unsuccessful clinical trial provides valuable information for our next step. Furthermore, what the public doesn’t see is that Alzheimer’s research has made amazing progress since the early 90’s in understanding the disease process; this understanding is critical for identifying effective therapeutic targets. From this work we are starting to see clearer strategies for providing early prevention. We should have an even greater understanding in the next 3-5 years from our basic research and clinical trials.

We have been thrilled to have two young researchers from WVU receive a new investigator grant from our national grants program in the past few years. How important is this new investigator category?

Without new investigators we will not have the workforce to continue the quests to understand and prevent this disease. These investigators are highly vulnerable to leaving science because of the lack of funding. As funding continues to decline, the new investigator is disproportionately affected because funding primarily goes to senior investigators. It is important to keep all investigators funded, both new and senior scientists; however we always need new investigators to continue the fight and bring new ideas to the field.

What most excites you in the area of Alzheimer’s research right now?

I find the new prevention trials just being started to be very exciting, particularly the DIAN-Treatment Unit (DIAN = Dominantly Inherited Alzheimer’s Network). We have reason to believe that currently developed drugs given at a much earlier stage of the disease may slow or stop the progression of Alzheimer’s. These newly launched trails could bring about an exciting change on how to treat Alzheimer’s disease.

When any of us make an investment…we want to see a good return on that investment. What would you say is the “return” on investment when someone chooses to make a donation to the Alzheimer’s Associations?

Research is the key to solving this terrible disease; The Alzheimer’s Association is the largest private funder of Alzheimer’s research. The success of our International Research Grants Program is our highly vetted grant awarding process to find and to fund the best research world-wide; no other organization does this. We have invested over $300 million dollars in research and have funded many of the key findings made in the Alzheimer’s field.

What can our readers do to help advance research as part of our overall mission?

Your readers can support research at many different levels: 1) Contact your state’s Congressman and urge them to support the National Alzheimer’s Plan by providing critical funding at the same levels as other healthcare issues such as heart disease, HIV, and diabetes, even during these difficult times in Washington. 2) Enroll in TrialMatch®, for we need both volunteers that are afflicted by the disease, and healthy volunteers. 3) Donate what you can financially and indicate that you want your contributions to go directly to research. 4) Indicate to others that Alzheimer’s disease is a major healthcare crisis that is coming and accelerating; convince them to get involved now and advocate for more research. We need your voice!
ALZHEIMER’S ASSOCIATION, WEST VIRGINIA CHAPTER
PUBLIC POLICY PRIORITIES – 2013

More than 48,000 West Virginians have Alzheimer’s disease or a related dementia, and this number is projected to grow 25 percent by 2025. West Virginia policymakers must act now to address the burden of Alzheimer’s on people with the disease, their families, caregivers, and the state.

1. **Implement the recommendations of the Make a Plan (MAP) for Alzheimer’s disease.** More than 50 state government, private, nonprofit, and community stakeholders have collaborated to develop a comprehensive plan of policy recommendations to enable West Virginia to become the nation’s first Alzheimer-capable state. Recommendations include:
   - Establishing licensure of adult day health services and ensuring they are a Medicaid-reimbursable service.
   - Work with the Legislature, Department of Military Affairs, Bureau of Senior Services, County Sheriff departments and local police departments to maximize the effectiveness of Silver Alert.
   - Devise incentives to recruit more physicians and mid-level providers into practicing geriatrics.

2. **Maintain $45,000 in state funding for the Alzheimer’s Association’s 24/7 Helpline.**
   - The 24/7 Helpline is a free service offering education and support for people with Alzheimer’s and their caregivers and is operated by trained staff members who understand the disease, its progression, and how it affects the physical and emotional health of people with the disease, as well as their families and caregivers.

3. **Protect and expand state respite funding for the Family Alzheimer’s In-Home Respite (FAIR) program.**
   - This critical, state-funded program offered in every county of West Virginia provides respite to family caregivers and delivers individualized attention and activities for the person with Alzheimer’s.
   - FAIR services help people with Alzheimer’s remain at home longer and can postpone the need for other costlier state services such as Medicaid.
   - Increased funding would allow West Virginia to serve more families and alleviate waiting lists that frequently exist.

For more information on these issues, contact:
Laurel Kirksey 304-343-2717
Director of Constituent Relations lkirksey@alz.org

ADD YOUR VOICE

Throughout the spring, Alzheimer’s Association advocates will rally during the West Virginia and Ohio legislative sessions, as well as at the annual Advocacy Forum in Washington, D.C. Advocacy efforts help to influence public policy to support caregiver needs such as providing respite, building an Alzheimer’s/dementia friendly workforce and increasing resources at the federal level for Alzheimer’s research. We need your voice! Join us in visiting your state’s legislature this spring, contact, Laurel Kirksey at 304.343.2717 or laurel.kirksey@alz.org to sign up!

WEST VIRGINIA

Alzheimer’s advocates will visit the West Virginia Legislature throughout the entire session this year, from February 13 – April 13. The list of visit dates will be posted at alz.org/wv by January 2013. We need your voice! Contact Laurel Kirksey, 304.343.2717 or laurel.kirksey@alz.org if you would like to join us this year to advocate on behalf of the 48,000 individuals with Alzheimer’s disease and the more than 108,000 caregivers in our state.

OHIO MEMORY DAY
COLUMBUS, OHIO
WED., APRIL 10

save the date
to share your voice and continue the fight.

advocacy forum 2013 | April 22-24
Renaissance Washington, D.C., Downtown Hotel
alz.org/forum
We are pleased to announce that the Alzheimer’s Association, West Virginia Chapter received a Claude Worthington Benedum Foundation Grant to address issues in the acute care setting.

In 2011 a group of 50 representatives from key stakeholder organizations and agencies from across West Virginia created the MAP or Make a Plan for Alzheimer’s in WV, it was recognized that the acute care setting should be addressed if this plan was to be truly comprehensive. The two recommendations that address the acute care setting are:

1. Implement “Alzheimer’s – informed” facility policies and procedures to create a system of “Universal Observations” to identify people with Alzheimer’s or a related dementia in healthcare settings so that people receive optimal inpatient care, as well as ambulatory medical services.

2. Develop a non-threatening, non-discriminatory system to identify people with Alzheimer’s disease in acute care settings in order to improve safety and quality of care.

Acute care may be defined as the place where a patient receives active “short term” treatment for an injury, an illness, an urgent medical condition or during recovery from surgery, unlike long-term care such as a nursing home. It can include the emergency room, hospital, outpatient surgery centers, and even some clinics. We often hear of challenges when a person with Alzheimer’s or a related dementia must be in the acute care setting.

Here is what we know. People with Alzheimer’s or a dementia sometimes need to go to the hospital. According to the Alzheimer’s Association’s 2010 Facts and Figures, people with a serious illness and Alzheimer’s go to the hospital more often than those with the same illness who do not have Alzheimer’s and their stays in the hospital are longer. Over and over we hear from caregivers the hospital stay for their loved one was complicated, and fraught with confusion. The sheer numbers of persons with dementia we expect to see in the coming years, combined with the complex medical and social factors impacting care mean that something needs to change.

In a recent abstract, May 2012, Dr. Holtzman, Department of Neurology, Washington University School of Medicine, St. Louis, Missouri, reported that dementia involves a long pre-clinical phase, and that providing treatment in the earliest phases is vital. Studies have demonstrated that hospital records often do not include the diagnosis of dementia even when it is known to be present, and additionally, the disorder can be present long before it is overtly diagnosed. Recognized dementia contributes to poorer outcomes for patients, and when it is present but NOT recognized those same poor outcomes will be magnified. Lack of recognition of dementia impacts safety within the hospital setting. For example, an aid moving a patient from one place to another who is unaware of a patient’s cognitive impairment may leave the patient unattended to wait for lab tests rather than alerting the lab staff to the patient’s arrival at the lab, to his/her status as cognitively impaired, and to the fact that he/she may be at risk for wandering or other unsafe behaviors. Lack of recognition of cognitive impairment and/or dementia can also lead to inappropriate treatment decisions and poor patient outcomes, including adverse events. Patients are often released too early or released into an inappropriate care environment, which in turn leads to readmission. A study released in June 2012 in the Annals of Internal Medicine reported that for those with Alzheimer’s disease a hospital stay could result in accelerated mental decline and increased risk of going into a nursing home or dying. Of the 800 people studied, being hospitalized was associated with nearly twice the likelihood of having a poor outcome, including mental decline and death. Being delirious while hospitalized increased risk by about 12 percent.

A workgroup of stakeholders is being formed and will include physicians, nurses, direct care staff, hospital social workers, as well as caregivers. The 18 month project will be called RAAC (Recognizing Alzheimer’s in Acute Care). We look forward to a thorough review of existing or previous efforts in both hospital and out-patient settings across the country, the development of a workable plan to be implemented in a later pilot project, and finally - improved safety and care for those with Alzheimer's or a related dementia.

We would like to express our sincere appreciation to the Claude Worthington Benedum Foundation for their foresight and generosity in the awarding of this grant.

Volunteers Needed!

Our dedicated volunteers are truly the key to our success! Volunteers increase our capacity to serve individuals and families facing this devastating disease, as well as support efforts to reach out to educate our community about Alzheimer's disease. We couldn't do it without your support! There are a variety of ways you can support the Alzheimer's Association as a volunteer! Here are just a few:

• Support group facilitator
• Walk to End Alzheimer's Planning Committee Member
• Office Support
• Helpline Volunteer
• Advocate
• Thanks for the Memories or Dancing Through Time Planning Committee Member

For more information about volunteer opportunities you can visit alz.org/wv or call 800.272.3900. To sign up to be a volunteer, contact Jennifer Waggener at 304.343.2717 or jennifer.waggener@alz.org.
An Alzheimer’s family support group is a regular gathering of caregivers, family and friends of individuals with Alzheimer’s disease and related dementias to discuss issues related to the disease and to caring for someone who has it. The purpose of a support group is to provide a non-threatening and non-judgmental place for participants to express their feelings and talk about their needs and concerns. A support group is a forum for exchanging information, getting practical ideas, learning about local resources and developing new friendships. Participation in a support group also provides emotional support. You’ll find people there who will listen and understand, so you are no longer alone. The Alzheimer’s Association wants to publicly thank all the facilitators who give so much of their time and energy to provide this positive opportunity for caregivers. Please call the Alzheimer’s Association at 800.272.3900 if you want to find a support group near you or endeavor to start a support group.

<table>
<thead>
<tr>
<th>Area</th>
<th>Date</th>
<th>Time</th>
<th>Location</th>
<th>Contact Name</th>
<th>Contact Phone</th>
<th>Email Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Athens, WV</td>
<td>Day</td>
<td>5:30 p.m.</td>
<td>Athens Community Center</td>
<td>Wendy Hamilton</td>
<td>304-865-6775</td>
<td><a href="mailto:wendy.hamilton@alz.org">wendy.hamilton@alz.org</a></td>
</tr>
<tr>
<td>Kanawha County, WV</td>
<td>Day</td>
<td>2:30 p.m.</td>
<td>Younger Onset Alzheimer's Support Group</td>
<td>J.T. Hunter</td>
<td>304-343-2717</td>
<td><a href="mailto:jt.hunter@alz.org">jt.hunter@alz.org</a></td>
</tr>
<tr>
<td>Mercer County, WV</td>
<td>Day</td>
<td>2:00 p.m.</td>
<td>Princeton Health Care Center</td>
<td>Emily Cozart</td>
<td>304-431-4216</td>
<td><a href="mailto:emily.cozart@phcconline.org">emily.cozart@phcconline.org</a></td>
</tr>
<tr>
<td>Raleigh County, WV</td>
<td>Day</td>
<td>2:00 p.m.</td>
<td>Raleigh County Commission on Aging</td>
<td>Terri Tilley</td>
<td>304-255-1397, ext. 133</td>
<td><a href="mailto:terri_tilley@raleighseniors.org">terri_tilley@raleighseniors.org</a></td>
</tr>
<tr>
<td>Jackson County</td>
<td>Day</td>
<td>12:30 p.m.</td>
<td>Amedisys Home Health</td>
<td>Cara Waybright</td>
<td>304-372-7590</td>
<td><a href="mailto:cara.waybright@amedisys.com">cara.waybright@amedisys.com</a> or Wendy.Hamilton, 304-865-6775, <a href="mailto:wendy.hamilton@alz.org">wendy.hamilton@alz.org</a></td>
</tr>
<tr>
<td>Putnam County, WV</td>
<td>Day</td>
<td>5:00 p.m.</td>
<td>Broadmore Assisted Living</td>
<td>Carol Cavender</td>
<td>304-757-4778</td>
<td><a href="mailto:carol.cavender@alz.org">carol.cavender@alz.org</a></td>
</tr>
<tr>
<td>Wood County, WV</td>
<td>Day</td>
<td>1:00 p.m.</td>
<td>Emmanuel Baptist Church</td>
<td>Judy Wildman</td>
<td>304-329-3195</td>
<td><a href="mailto:wildman3@atlanticbb.net">wildman3@atlanticbb.net</a></td>
</tr>
<tr>
<td>Fayette County, WV</td>
<td>Day</td>
<td>2:00 p.m.</td>
<td>Hidden Valley Center</td>
<td>Stacy Cooper</td>
<td>304-465-1903</td>
<td><a href="mailto:stacy.cooper@genesishcc.com">stacy.cooper@genesishcc.com</a></td>
</tr>
<tr>
<td>Hancock County, WV</td>
<td>Day</td>
<td>6:00 p.m.</td>
<td>Weirton Geriatric Center</td>
<td>Mary Ann Boyd</td>
<td>304-723-4300</td>
<td><a href="mailto:wgcmboyd@comcast.net">wgcmboyd@comcast.net</a></td>
</tr>
<tr>
<td>Harrison County, WV</td>
<td>Day</td>
<td>10:30 a.m.</td>
<td>Harrison County Senior Center</td>
<td>Judy Labdik</td>
<td>304-363-2500</td>
<td><a href="mailto:judy.a.labdik@wv.gov">judy.a.labdik@wv.gov</a></td>
</tr>
<tr>
<td>Marion County, WV</td>
<td>Day</td>
<td>2:00 p.m.</td>
<td>John Manchin Senior Health Care Center</td>
<td>Judy.A.Labdik</td>
<td>304-363-2500</td>
<td><a href="mailto:judy.a.labdik@wv.gov">judy.a.labdik@wv.gov</a></td>
</tr>
<tr>
<td>Marshall County, WV</td>
<td>Day</td>
<td>5:30 p.m.</td>
<td>Marshall County Senior Center</td>
<td>Shirley Sisarcick</td>
<td>304-232-6730</td>
<td><a href="mailto:ssisarcick@ovrh.org">ssisarcick@ovrh.org</a></td>
</tr>
<tr>
<td>Morgan County, OH</td>
<td>Day</td>
<td>2:00 p.m.</td>
<td>Highland Oak Health Center</td>
<td>Kayla Hite</td>
<td>740-962-3761</td>
<td><a href="mailto:kayla.hite@highlandoaks.hc.com">kayla.hite@highlandoaks.hc.com</a></td>
</tr>
<tr>
<td>Morgan County, WV</td>
<td>Day</td>
<td>2:00 p.m.</td>
<td>Senior Life Services</td>
<td>Doris Rink</td>
<td>304-258-3096</td>
<td><a href="mailto:dorisr@frontier.com">dorisr@frontier.com</a></td>
</tr>
<tr>
<td>Ohio County, WV</td>
<td>Day</td>
<td>5:30 p.m.</td>
<td>MJ Viola Senior Center</td>
<td>Shirley Sisarcick</td>
<td>304-232-6730</td>
<td><a href="mailto:ssisarcick@ovrh.org">ssisarcick@ovrh.org</a></td>
</tr>
<tr>
<td>Preston County, WV</td>
<td>Day</td>
<td>7:00 p.m.</td>
<td>Heartland of Preston</td>
<td>Judy Wildman</td>
<td>304-329-3195</td>
<td><a href="mailto:wildman3@atlanticbb.net">wildman3@atlanticbb.net</a></td>
</tr>
<tr>
<td>Putnam County, WV</td>
<td>Day</td>
<td>5:00 p.m.</td>
<td>Broadmore Assisted Living</td>
<td>Carol Cavender</td>
<td>304-757-4778</td>
<td><a href="mailto:carol.cavender@alz.org">carol.cavender@alz.org</a></td>
</tr>
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<td>Day</td>
<td>2:00 p.m.</td>
<td>Raleigh County Commission on Aging</td>
<td>Terri Tilley</td>
<td>304-255-1397, ext. 133</td>
<td><a href="mailto:terri_tilley@raleighseniors.org">terri_tilley@raleighseniors.org</a></td>
</tr>
<tr>
<td>Randolph County, WV</td>
<td>Day</td>
<td>6:30 p.m.</td>
<td>Colonial Place</td>
<td>Melissa Kilgore</td>
<td>304-636-8600</td>
<td><a href="mailto:kilgorebrian@gmail.com">kilgorebrian@gmail.com</a></td>
</tr>
<tr>
<td>Upshur County, WV</td>
<td>Day</td>
<td>2:00 a.m.</td>
<td>St. Joseph's Hospital</td>
<td>Debbie Dean or Donna Lewis</td>
<td>304-473-2000 or <a href="mailto:dlewis@stj.net">dlewis@stj.net</a></td>
<td></td>
</tr>
<tr>
<td>Washington County, OH</td>
<td>Day</td>
<td>6:00 p.m.</td>
<td>Marietta Center Care and Rehabilitation Center</td>
<td>Pamela Parsons</td>
<td>304-373-4232</td>
<td><a href="mailto:PamelaParsons@sunh.com">PamelaParsons@sunh.com</a></td>
</tr>
<tr>
<td>Wood County, WV</td>
<td>Day</td>
<td>1:00 p.m.</td>
<td>Rockland United Methodist</td>
<td>Debbie Dean or Donna Lewis</td>
<td>304-473-2000 or <a href="mailto:dlewis@stj.net">dlewis@stj.net</a></td>
<td></td>
</tr>
<tr>
<td>West Virginia</td>
<td>Day</td>
<td>6:00 p.m.</td>
<td>The Manor Dining Room</td>
<td>Melissa Kilgore</td>
<td>304-636-8600</td>
<td><a href="mailto:kilgorebrian@gmail.com">kilgorebrian@gmail.com</a></td>
</tr>
<tr>
<td>West Virginia</td>
<td>Day</td>
<td>2:00 p.m.</td>
<td>The Manor Dining Room</td>
<td>Melissa Kilgore</td>
<td>304-636-8600</td>
<td><a href="mailto:kilgorebrian@gmail.com">kilgorebrian@gmail.com</a></td>
</tr>
</tbody>
</table>

Please call to determine eligibility and under in early stages.)
Tributes

The Alzheimer’s Association, West Virginia Chapter gratefully acknowledges the donors whose honorary and memorial contributions to the Chapter were received from 7/1/2012 - 9/30/2012. For information on tributes and memorials, contact Evan Osborn, 800.272.3900 or evan.osborn@alz.org

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Carole Yelton

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Albert & Irene Goff
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Ina & Boyd Humphrey
Jane Marks

JOY WILLIAMS
James P. Hayes

SARAH YOUNG
Trish Owen

Honoring Your Loved Ones

For many, the greatest way they can pay tribute to their loved one with Alzheimer’s, living or deceased, is through a gift to their favorite charity. We deeply appreciate gifts you make to the Alzheimer’s Association, West Virginia Chapter in honor or in memory of your loved one.

Many families choose gifts in lieu of flowers as a way of honoring a family member who has passed away as a result of Alzheimer’s disease or a related dementia. If this is something your family is interested in doing, please ask the mortuary in charge of services to contact us – or contact us directly – for information on listing the West Virginia Chapter in your loved one’s obituary and for a supply of tribute envelopes.

If you have another occasion for which you wish to pay tribute to a loved one, we will be happy to send you envelopes, as well. Your gift helps other families struggling with the challenges of Alzheimer’s.

For more information contact, Evan Osborn, 800.272.3900 or evan.osborn@alz.org
Help During the Holiday, from page 6

HOW THE PERSON WITH DEMENTIA CAN PARTICIPATE

- Involve the person in safe, manageable holiday preparation activities. Begin slowly by asking the person to help you prepare easy foods such as washing the grapes or laying out crackers. The person may be able to help wrap packages by holding the tape or using their finger to help tie the bow. Maybe he can hand you decorations or set the table. (Avoid using candies, artificial fruits/vegetables or other edibles as decorations. Blinking lights may confuse or scare the person.) Again, change may need to occur, but it does not mean you should not decorate, nor let your loved one help.

- Maintain the person’s normal routine so that holiday preparations don’t become disruptive or confusing. Taking on too many tasks can wear on you and the person.

- Build on past traditions and memories. Your family member may find comfort in singing old holiday songs, for example. But also experiment with new holiday traditions, such as renting seasonal videos.

- Focus on holiday activities that are meaningful to the person, such as signing favorite holiday songs, reading scripture, or eating traditional holiday foods; this may be more meaningful than attending a social event that may be overwhelming.

- Ask a clergy member if they would hold a brief service at a quiet time at your place of worship or at your home.

- Depending on his or her abilities, get the person involved in giving gifts. For example, someone who once enjoyed cooking may enjoy baking cookies and packing them in tins or boxes. Or, you may want to buy the gift and allow the person to wrap it.

- Plan time for breaks so the person can rest in a quiet area away from noise and crowds.

LOVED ONE IS IN THE HOSPITAL/FACILITY OVER THE HOLIDAY

- If children are visiting, let the kids unwrap a few gifts by your loved one’s bedside so he or she can see the joy on their faces.

- Decorate the room with holiday wreathes, garlands, strings of lights (Check with hospital staff before doing so).

- Bring a photo album or scrapbook full of pictures from holidays past and reminisce with your loved one.

- Gather family together for a holiday sing-along in your loved one’s room.

- Listen to a recording of a religious service together.

- Play your loved one’s favorite holiday music.

- Create a sachet of fragrant dried balsam pine needles so your loved one can enjoy the Christmas tree smell.

- Bring your loved one’s favorite holiday treat to enjoy together (diet permitting).

- Watch a favorite holiday movie together, or, better yet, watch home videos of holidays passed.

- Bring a few special ornaments for your loved one to hold and discuss the memories associated with each. Even if your loved one can’t be home to help decorate the tree, seeing and touching the ornaments can bring back wonderful memories.

As caregivers you may strive to find the perfect balance between caregiving responsibilities and maintaining holiday traditions. But perfect may not be possible. The bottom line is, things may be different this year, but we can still have meaningful and special holiday experiences. It will involve some AA - adapting and adjusting- on your part but with these helpful tips families can make the holiday experience enjoyable and meaningful for the whole family!!
Never Say Never, from page 7

- Register the person in a program for safety. Those offered by the Alzheimer’s Association are as follows:
  - MedicAlert® + Alzheimer’s Association Safe Return® is a nationwide identification program designed to save lives by facilitating the safe return of those who wander.
  - Comfort Zone® and Comfort Zone Check-In® allows families to monitor a person with dementia’s whereabouts remotely using Web-based location services.
  - Go to Alzheimer’s Navigator and take the safety survey to receive a free, customized home safety checklist, alz.org.
  - Access our HELPLINE Contact Center 24/7 at 800.272.3900.
  - In addition, West Virginia has 48 counties supported by Project LifeSaver. Project Lifesaver provides police, fire/rescue and other first responders with a comprehensive program including equipment and training to quickly locate and rescue “at risk” individuals with cognitive disorders who are at constant risk to the life threatening behavior of wandering including those with Alzheimer’s disease, Autism, and Down syndrome.

Tips to prevent wandering

Wandering can happen, even if you are the most diligent of caregivers. Use the following strategies to help lower the chances:

- Having a routine can provide structure. Create a daily plan and stick to it as much as possible.
- Identify the most likely times of day that wandering may occur. Plan activities at that time. Activities and exercise can reduce anxiety, agitation and restlessness.
- Reassure the person if he or he feels lost, abandoned or disoriented. If the person with dementia wants to leave to “go home” or “go to work,” use communication focused on exploration and validation. Refrain from correcting the person. Reassure and acknowledge instead. For example, “We are staying here tonight. We are safe and I’ll be with you. We can go home in the morning after a good night’s rest.”
- Ensure all basic needs are met. Has the person gone to the bathroom? Is he or she thirsty or hungry?
- Avoid busy places that are confusing and can cause disorientation. This could be a shopping malls, grocery stores or other busy venues.
- Place locks out of the line of sight. Install either high or low on exterior doors, and consider placing slide bolts at the top or bottom.
- Visit alz.org/safety for more tips on wandering.

As with so many things, we must take appropriate precautions. it is better to have a plan for a situation we hope we never have to face. Never say “never.”
The Alzheimer's Association, West Virginia Chapter, is committed to support services, education, advocacy and research on behalf of those affected by Alzheimer's.

Name: ___________________________________ Phone: ____________________
Address: ________________________________________________________________
City: ___________________________ State: ___________ Zip: ___________
Email: ________________________________________________________________
☐ $10  ☐ $25  ☐ $50  ☐ $100  ☐ $500  ☐ $1500  Other: _________

Please designate as follows:
In memory of ___________________________________________________________
In honor of ___________________________________________________________

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