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FROM THE DESK OF...
Donna McGowan, Executive Director

The Alzheimer's Association Rhode Island Chapter's Caregiver's Journey Conference Committee has been given the task of selecting high-quality presenters for our ninth annual Caregiver's Journey Conference on April 25.

This conference is for both caregivers and professionals who dedicate their lives to caring for people with Alzheimer's Disease (AD) and other dementias. Caregivers are a diverse group. One size does not fit all. Yet, as different as we are, one aspect unites us: our concern for the quality of care for the people in our charge. Caring for someone with Alzheimer's disease or a related dementia is truly a labor of love.

Every family caregiver knows the shockwave that phone call at 3:00AM can bring. "Have the police found my dad wandering miles from home - or worse?" "Is mom being disruptive and fighting with staff in her long-term care facility again?" "Has my sister reached the breaking point taking care of our aging father?" These scenarios are, sadly, too familiar for the more than 53,000 family caregivers in Rhode Island. It is estimated that, last year, over 16.1 million family caregivers across the nation provided 18.4 billion hours of unpaid care to loved ones with Alzheimer's, eliminating an enormous institutional burden. This is a contribution to the nation valued at over $232 billion. What would happen to the system if we were no longer able to provide this kind of care to our loved ones? We bear an enormous responsibility-equal only by our contributions to America's healthcare system. Similarly, professional caregivers - those who work in assisted living facilities, nursing homes and hospitals, adult day services and community based programs and as private aides assisting families in their homes - bring a special set of skills and expertise, without which the system would suffer. (2018 Facts and Figures)

From our 24-hour Helpline (800-272-3900) to our diverse number of support groups, and from our dementia training for medical professionals to our free care educational seminars, the Chapter rightly places the highest priority on making sure that caregivers-unpaid and professional-have the tools to get the job done. Whether you are a family caregiver, a seasoned professional caregiver, or are new to the field, this conference promises to offer you the best and most interesting topics and presenters. Be sure to share your story today. Share your experience living with Alzheimer's or caring for a loved one with the disease; we may have opportunities for you to speak through our local Alzheimer's Association speakers bureau. We may also have opportunities for you to share your experiences with local and national media outlets. Your stories are powerful!

Special thanks to our sponsors in part: the Division of Elderly Affairs, RI Department of Human Services, with funds from the U.S. Administration on Aging and our Keynote Sponsor, Rhode Island Geriatric Education Center. We are pleased to announce our keynote address "Dementia: It is not a Person's Name" will be presented by Joshua Freitas, M.Ed, BC-DEd, CAEd. This year, during lunch time we will have an update on the Rhode Island State Plan on Alzheimer's Disease and Related Dementias from Craig Dwyer of the Lt. governor's office. In addition, we are offering a variety of workshops presented by experts in the field of Alzheimer's care. On behalf of our Conference committee, our Board, our staff and most importantly the people we serve, I thank you for your loyal and consistent support. I look forward to greeting you at the conference!
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1 IN 3
seniors dies with Alzheimer’s or another dementia
It kills more than breast cancer and prostate cancer COMBINED

24/7 Helpline
Call us day or night
1.800.272.3900
TTY: 1.866.403.3073
Here are just some of the services we offer:

**A Care Consultation** is an individualized meeting with one of our dementia experts to learn about dementia, get connected with services in your area, troubleshoot specific problematic scenarios, and develop strategies for the future. We offer this service at no-cost over the phone or in our office.

**Our Early Stage Social Engagement** program is designed for persons who have been diagnosed with early memory loss to enhance the quality of life for participants.

**Caregiver Support Groups** provide care partners with an opportunity to share stories, information and resources with each other in a confidential environment. There is no attendance requirement, so feel free to come just once to check it out, or every time the group meets. There are more than 20 support groups throughout the state.

**Our Chapter Library** has a wide range of books, brochures, articles, and videos on all aspects of Alzheimer's available anytime on loan.

**Our Education Calendar** provides information on education and training sessions for virtually everyone - the general public, family caregivers, individuals with dementia and healthcare professionals. Our classes cover a range of topics: The Basics about Alzheimer's disease, Understanding Dementia-Related Behaviors and Effectively Communicating, Healthy Habits for Your Brain and Body, Know the 10 Warning Signs of Alzheimer's disease, and more! If you're not sure which class will teach you what you need to learn, give us a call and we can recommend the class for you! Visit communityresourcefinder.com to search for upcoming educational programs.

**Medic Alert+Safe Return** is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency. Learn more at medicalert.org/safereturn

**Our Chapter Website** is an on-line resource with links to local programs and services, research, events and on-line education: alz.org/ri
Caring for someone with Alzheimer’s disease is a labor of love. The Alzheimer’s Association can help! The Rhode Island Chapter is pleased to announce the return of our annual Caregiver’s Conference. The 2019 all-day free conference for caregivers, named “Caregiver’s Journey” will take place at the Crowne Plaza Hotel, Warwick on April 25, 2019 from 8:00AM-4:30PM. The conference provides healthcare professionals and caregivers with the tools they need to carry on their journey of supporting someone with dementia.

With the prevalence of Alzheimer’s disease on the rise, the “Caregiver’s Journey” conference is timely. The demands on a person taking care of elderly parents, spouses, or friends can result in a great deal of stress.

This year’s conference will feature the keynote address “Dementia: It is not a Person's Name” presented by Joshua Freitas. Dr. Freitas is Vice President of Program Development at CERTUS Senior Living in Orlando, Florida. Formally with Benchmark Senior Living, he is an award-winning memory care program developer, researcher, and author. His care and training philosophies have been featured in prominent publications, including Long-Term Living Magazine, Healthcare Provider Magazine, Science Today Magazine, television talk shows, and much more.

In addition to the keynote address, the conference will offer a variety of workshops with topics ranging from “Behaviors: The Good, Bad and How to Support Creative Interventions,” “The Grief Journey of Dementia Caregivers,” “Dementia 101,“ “What Matters Most to You? Advanced Care Planning for End Of Life Decisions,” “Legal and Financial Planning: Consideration When Caring for People with Dementia,” “Now What? Unique Considerations in Providing Support for People with Intellectual Disabilities and Dementia,” ”When It’s No Longer Safe to Drive,” “A Walk in Their Shoes: Virtual Tour” and more! There will also be more than 40 vendors providing resources related to Alzheimer’s care.

If you are a caregiver or healthcare professional, or want to learn more about Alzheimer's disease, you don’t want to miss this!

On-site respite is available for your loved one with Alzheimer’s disease, with advanced registration.

Visit our website at alz.org/ri to register online or call 800.272.3900 to receive a brochure. Although the conference is free to family caregivers, advanced registration is required. There is a fee for professionals and those who wish to receive contact hours. More information can be found at communityresourcefinder.com. Online registration is required.
Here is a preview of some of the workshops that will be offered at the Caregiver's Journey Conference. Register by visiting alz.org/tri or at communityresourcefinder.com call 800.272.3900.

**Walk in their Shoes: Virtual Tour**
Guides will take you through an experience to better create a positive environment for those with dementia. We will discuss general challenges one faces with a dementia diagnosis and topics such as depression, arthritis, visual impairment and information regarding our use of oxygen levels when we are stressed. You will be guided through the challenges of compromised vision, hearing and dexterity which all affect cognition.

**Behaviors: The Good, Bad and How to Support Creative Interventions**
This program will first share the importance of identifying the care-giving team. We will be discussing non-pharmacological approaches in supporting individuals who exhibit behaviors that manifest as a need or a distress. We will also be working through how we, as caregivers, can support the challenges of two common transitions: a residential move and the introduction of outside caregivers. A behavior map will be introduced which will give a step by step intervention plan supporting the family, front line associates in a communities or agencies.

**Legal and Financial Planning**
Learn answers to some important questions, such as “How can I protect assets if a nursing home placement becomes necessary?” “Is guardianship necessary?” Legal tools for the caregiver will be discussed, as well as myths that prevent caregivers from effectively managing the affairs and protecting the assets of loved ones.

**Dementia 101**
This workshop will provide an overview of Alzheimer’s disease and related dementias. This includes the prevalence of Alzheimer's disease, stages of progression and examples of symptoms from beginning to late stage.

**Be An Empowered Caregiver**
Do you know there are Federal and State funded programs to provide financial assistance? Do you know how to access them? Do you think you may qualify? If you answered NO to any of these questions, then you need to attend this workshop.

**Now What? Unique Considerations in Providing Support for People with Intellectual Disabilities and Dementia**
This workshop will provide the participants with an overview of unique considerations that are encountered by people with ID and their care partners (whether paid and unpaid) throughout this ‘continuum of dementia,’’ starting with early suspicion and inclusion in dementia-friendly communities. To address this need in Rhode island, a resource guide has been developed through a federal grant by Seven Hills Rhode Island. The session will include discussion of the guide, the maintenance of crucial relationships and a focus on meaningful activity, the quality of life for a person with ID and dementia can be enhanced through the duration of the disease process.

**Bring Back The Joy: The Power of Music**
Strategies to enhance communication between people living with dementia and their care providers to reduce isolation and provide meaning and purpose despite illness and debility. Demonstration on how to facilitate reminiscence with both cognitively intact and cognitively impaired adults.

**Care Planning**
Needs change at different stages of the disease. Each family’s situation is unique. This workshop will provide initial guidelines about key information, resources and care planning.

**The Grief Journey of Dementia Caregivers**
The incremental losses associated with caregiving for a person with dementia cause in us two types of grief responses simultaneously. The immediate grief that comes with the many losses accumulating as the dementia advances is accompanied by anticipatory grief that is due to our keen sense of the inevitable death ahead. Use of caregiver grief inventories can assist caregivers and the professionals working with them to identify grief responses and improve self awareness and self care for as they continue the arduous caregiver journey.

**When It’s No Longer Safe To Drive**
AAA Northeast's Manager of Public Affairs and Traffic Safety will present information on local resources that can guide individuals and caregivers through driving cessation while respecting quality of life.
Signing up for Alzheimer's Association TrialMatch® Is Easy

Step 1: Access TrialMatch at alz.org/TrialMatch or call 1.800.272.3900

Step 2: Complete a brief questionnaire to create a profile

Step 3: The Alzheimer's Association will compare your unique profile to its comprehensive, continually updated study database

Step 4: You will receive information about studies for which you may be a good fit based on your preferences, location, and personal demographics

If you'd like more information, please call our Helpline at 1.800.272.3900.

Rhode Island Alzheimer’s Disease Research Conference

Thursday, April 25, 2019
The Crowne Plaza Hotel | Warwick, RI

This is a one-day conference for both community-based clinical care providers, as well as active researchers, all of whom provide care for patients and families afflicted by Alzheimer’s disease. This conference will bring together the major research groups across the state’s public and private institutions, to share ideas, resources, and opportunities. Community-based caregivers will learn about exciting research advances and clinical trials that their patients might benefit from, and they will be provided with timely updates on state-of-the-art advances in the field. Graduate students, medical students and fellows will be able to meet, share ideas, and to present new experimental results through a poster session that highlights their work.

Attendees should include physicians who are both researchers and clinical, PhD researchers, post docs, medical residents and students.

The goals of the conference are to be able learn to recognize the use of new approaches to cognitive testing in the detection of pre-clinical dementia and recognition of early Alzheimer’s disease, describe the current scientific evidence for the impact of lifestyle interventions on brain health and dementia, with focus on physical fitness and dietary interventions, and apply the updated diagnostic criteria for age-associated memory impairment, mild cognition impairment, and Alzheimer’s disease on the epidemiology of cognitive disorders

Any professionals interested in the Research Conference should contact Annie Murphy at the Alzheimer’s Association or go to communityresourcefinder.org to register or contact us at 1-800-272-3900.
The Alzheimer’s Association has awarded more than $800,000 to support the SPRINT MIND 2.0 Study, which will further investigate the impact of intensive blood pressure treatment on reducing risk of dementia. The newly funded study will continue and extend follow up of the SPRINT MIND trial participants.

SPRINT MIND, which published its results Monday, January 28, 2019 in the Journal of the American Medical Association (JAMA), is the first randomized clinical trial to demonstrate that intensive treatment to reduce blood pressure can significantly reduce the occurrence of mild cognitive impairment (MCI).

“SPRINT MIND 2.0 and the work leading up to it offers genuine, concrete hope,” said Maria C. Carrillo, Ph.D., Alzheimer’s Association Chief Science Officer. “MCI is a known risk factor for dementia, and everyone who experiences dementia passes through MCI. When you prevent new cases of MCI, you are preventing new cases of dementia.”

However, the study’s outcome on reducing risk of dementia was not definitive. The estimated reduction in risk for dementia was in the same direction and of the same magnitude as MCI, but it was not statistically significant, though there was a positive trend. According to the researchers, the success of the heart disease portion of trial resulted in early termination of the intense intervention meant the duration of the study was not long enough to definitively answer the dementia question.

Island Chapter, to find the resources within the Association and the community to support the family.

The Alzheimer’s Association is taking rapid action to build on these results by providing seed funding for SPRINT MIND 2.0, an extension of the SPRINT MIND study that will re-engage the original trial’s participants. SPRINT MIND 2.0 adds two years of follow-up and assessment to allow for a more definitive statement on reducing dementia risk.

With this financial commitment, the Alzheimer’s Association enables SPRINT MIND 2.0 to begin in early 2019, which will make results available approximately one year earlier than anticipated with other funding sources. Discussions with other potential funders are ongoing.

“The Alzheimer’s Association is committed to getting the answers about treating and preventing Alzheimer’s and other dementias. We are filling the gaps in Alzheimer’s research, and - with the support of our donors and partners - we act rapidly to maximize opportunities,” Dr. Carrillo added. “Proof that lowering blood pressure can lower risk for dementia may be key to improving the lives of millions of people around the world.”

SPRINT MIND compared two strategies for managing hypertension in cognitively healthy older adults: an aggressive strategy versus a standard care strategy. The intensive strategy used a systolic blood pressure goal of less than 120 mm Hg. The standard care strategy used a goal of less than 140 mm Hg.
FROM THE DESK OF...
Annie Murphy, MA, Program Manager

OUR NEWLY UPDATED Trainer Program

I am excited to report our comprehensive Train the Trainer Program, Caring for Individuals with Alzheimer's Disease: A Habilitation Training Curriculum has undergone its third revision, and it now incorporates quality care practices based on a comprehensive review of current evidence, best practices and a panel of expert opinions.

Our new curriculum is a train-the-trainer model created to prepare attendees, already familiar with Alzheimer's and dementia care, to train direct care staff in a wide range of care settings. The seven-hour training teaches attendees the 13-hour curriculum based on the person-centered model of Habilitation Therapy.

This curriculum has been recognized and approved by the Alzheimer's Association.

The 2018 Dementia Care Practice Recommendations were developed to better define quality care across all care settings and throughout the disease course. They are intended for professional care providers who work with individuals living with dementia and their families in residential and community-based care settings. The Practice Recommendations are published as a February 2018 supplement to The Gerontologist.

Anyone can go to www.alz.org/dementia to find more information about dementia.

Visit communityresourcefinder.org in March 2019 to register direct care staff to attend this training or contact me at the Rhode Island Chapter office with questions at 1-800-272-3900 or by email at mmurphy@alz.org.

Many individuals who have attended the training in the past may be eligible to purchase the new updated training manual without having to attend again. The following criteria has to be met:

1. Attended an Alzheimer's Association train-the-trainer program within the last five years through the the Alzheimer's Association Rhode Island chapter.

2. The Alzheimer's Association Rhode Island Chapter can confirm attendance.

Professionals using the former train-the-trainer manual will have to purchase the new manual by May 1, 2019. After May 1, the former training is no longer recognized by the Alzheimer's Association as a professional training.

New Support Group in Pawtucket to begin 3/27

A new support group will be held the last Wednesday of each month, starting on March 27, at the Leon Mathieu Senior Center located at 420 Main Street in Pawtucket on the 2nd Floor from 10-11 a.m.

Register at communityresourcefinder.org. The facility is handicap accessible.

to confirm time and dates contact the Leon Mathieu Senior Center at 728-7852.
Hopes for a world without Alzheimer's disease

By Joanne Comeau

Ask elementary school teacher David Creamer, who lives in Seekonk, about his father and you’re sure to get a smile. But sadly, David’s father Edward passed away from Alzheimer’s Disease in 2016, after a 5-year battle.

David shares his story as a caregiver and an Alzheimer’s/dementia care specialist with support groups offered around Rhode Island to help others understand and deal with the responsibilities that come to family and friends who must assist a loved one with Alzheimer’s. The family first noticed Edward exhibiting strange behaviors, like buying large quantities of cleaning supplies and placing smoke detectors all over the house. The family wondered if these behaviors were at all related to Edward’s loss of hearing. But when they took him to his primary care physician, the doctor indicated that the symptoms appeared to be more than hearing related.

Edward was taken to a memory specialist who ran a number of tests and advised the family that the diagnosis was Alzheimer’s Disease. David and his family worked as a team to put a care plan in place. David’s brother Glenn handled the financial and legal aspects, such as the will and power of attorney. David’s wife Claire had a nursing background, so she dealt with the medical professionals. And David was the one who reached out to the Alzheimer’s Association, Rhode Island Chapter, to find the resources within the Association and the community to support the family.

One aspect of the plan was a move for Edward and his wife Lorraine from their Pawtucket home of over 40 years to an Assisted Living facility. It had become clear that Lorraine needed more support in the role she had as primary caregiver. It was a difficult decision, but as the disease progressed, so did the need for increased care. Burnout can easily occur with Alzheimer’s caregivers. David found that attending support groups for caregivers and his workouts at the YMCA were helpful in alleviating stress.

David thinks about working in the memory field at some point. For now, he hopes that a cure for Alzheimer’s will be found so that his grandchildren can live in a world without it.

Joanne Comeau is a volunteer with the Alzheimer’s Association Rhode Island Chapter.
EDUCATION CALENDAR

The Basics: Memory Loss, Dementia and Alzheimer's disease
Alzheimer's disease is not a normal part of aging. If you or someone you know is affected by Alzheimer's disease or dementia, it's time to learn the facts. This program provides information on detection, causes and risk factors, stages of the disease, treatment, and much more.

April 23 6pm-7:30pm
Beechwood Center for Life Enrichment
44 Beach Street, North Kingstown

Understanding and Responding to Dementia Related Behaviors
During the stages of dementia, the person diagnosed often will experience changes in behavior that can be confusing for a caregiver. Behaviors are a form of communication and are essential to understanding the needs of the person with dementia.

May 7 6:00pm-7:30pm
Beechwood Center for Life Enrichment
44 Beach Street, North Kingstown

Legal and Financial Planning on Alzheimer's disease
If you or someone you love is affected by Alzheimer's disease or dementia, the time for legal and financial planning is now. Learn more about the legal and financial issues to consider and how to put effective plans in place.

March 19 3:30pm-5:00pm
Beechwood Center for Life Enrichment
44 Beach Street, North Kingstown

May 21 6:00pm-7:30pm
Beechwood Center
44 Beach Street, North Kingstown

Get the emotional support you need!
Support groups are regularly scheduled, free gatherings of persons who are providing care for persons with Alzheimer's disease or a related disorder. The groups are facilitated by persons trained by the Alzheimer's Association and are held throughout the state in community-based settings.

For a full listing of support groups in Rhode Island please visit communityresourcefinder.org

LGBTQ Phone Support Group
Join other LGBTQ spouses and partners to support one another while receiving information and resources on Alzheimer's disease and related dementias.

Held the first Monday of every month for partners and spouses of people living with dementia. For details on timing and call-in information, please contact the facilitator, Barb Meehan at 508.291.0660 or bamscats@gmail.com.
Powerful Tools for Caregivers*
Are you a caregiver providing assistance to an adult with a developmental disability and dementia? Join us for this award-winning education program has helped family caregivers restore the balance between caring for others and caring for themselves.

Thursday Mornings May 2-June 6 10:00am-11:30am
Bliss Properties
245 Waterman Street, Suite 506, Providence

Each morning will feature a new topic:

Taking Care of You
Identifying and Reducing Personal Stress
Communicating Feelings, Needs and Concerns
Communicating in Challenging Situations
Learning From Your Emotions
Mastering Caregiving Decisions

Healthy Living for Your Brain and Body
For centuries, we've known that the health of the brain and the body are connected. But now, science is able to provide insights into how to make lifestyle choices that may help you keep your brain and body healthy as you age. Join us to learn about research in the areas of diet and nutrition, exercise, cognitive activity and social engagement, and use hands-on tools to help you incorporate these recommendations into a plan for healthy aging.

March 26 3:30-5:00pm
Beechwood Center for Life Enrichment
44 Beach Street, North Kingstown

June 11 6:00-7:30pm
Beechwood Center for Life Enrichment
44 Beach Street, North Kingstown

Care Planning For Families Through the Stages Of Dementia
Join Bill Kirkpatrick, LICSW to hear how the care needs change at different stages of the disease and why and how each family's situation is unique. Begin to understand what types of decisions will need to be met during each stage of the disease and why it's important to plan for these stages of change. This workshop will provide initial guidelines on key information, resources available and care planning decisions. This presentation is meant for people who have been recently diagnosed, their family members and people new to the profession of caring for people with Alzheimer's or other related dementia.

March 5 6:00pm-7:30pm
Bliss Properties
245 Waterman Street, Providence

Westerly Community forum
The Alzheimer's Association is here to help. Learn about programs and services offered by the Association to help you live with or care for someone with dementia. Bring a friend who has been affected by the disease. Share your thoughts about how we can help people in your community. Registration is required.

March 27 3:00pm-5:00pm
Ocean Community Chamber of Commerce
1 Chamber Way, Westerly

Challenging Behaviors: The Good, Bad and How To Support Creative Interventions
This program will first share the importance of identifying the care-giving team. We will be discussing non-pharmacological approaches in supporting individuals who exhibit behaviors that manifests as a need or distress. We will also be working through how we, as caregivers, can support the challenges of two common transitions: a residential move and the introduction of caregivers. A behavior map will be introduced which will give a step by step intervention plan supporting the family, front line associates in a communities or agencies.

May 17, 18 9:30-11:00am
Warwick Library
600 Sandy Lane, Warwick

PLEASE NOTE
Except where noted, all programs are open to the public. Registration is required by calling 1.800.272.3900 or visit communityresourcefinder.org unless otherwise noted.

*This project was supported, in part by grant number 90AL0014-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.
Early Stage Social Engagement Program
A group for active people with early memory loss

Life takes turns. It helps to have friends around every corner. Get out, get active, and get connected with the Alzheimer's Association Early Stage Social Engagement program offered in five locations throughout Rhode Island.

Eligibility:
• A diagnosis of mild cognitive impairment, early Alzheimer’s or other early memory disorder
• A desire to participate in social activities and increase physical fitness
• A willingness to acknowledge memory loss and learn ways to manage it

A meeting with Alzheimer's Association staff is necessary to determine eligibility. Please contact Program Manager Annie Murphy for more information and to learn about the benefits of participating in this program at 1.800.272.3900 or mmurphy@alz.org.
Alongside advocates, the Alzheimer’s Association, Rhode Island Chapter will host an Advocacy Day at the state capitol on Tuesday, May 7, to discuss Alzheimer’s disease and its impact on Rhode Island. According to the Alzheimer’s Association 2018 Alzheimer’s Disease Facts & Figures report, there are 23,000 people living with Alzheimer’s and 53,000 Alzheimer’s caregivers in Rhode Island.

The Advocacy Day will provide opportunities for advocates to meet face-to-face with their state elected officials. Advocates will share their personal stories of how Alzheimer’s has impacted their lives with state policymakers. Advocates will also have a chance to rally behind State Alzheimer’s legislation that would establish Rhode Island’s State Plan to address Alzheimer’s disease, create an advisory council, and establish a training requirement for medical professionals. The keynote speech will be delivered by Lieutenant Governor Daniel McKee. as well as state legislative champions.

“Our federal legislators are increasingly making research, care and support for Alzheimer’s disease a priority; from the development of the National Alzheimer’s Plan in 2012 to the passage of a $100 million increase in research and infrastructure funding through the passage of the 2018 BOLD Act,” said Donna McGowan, Executive Director of the Alzheimer’s Association, Rhode Island Chapter. “We are confident our state legislators will see the significance of maintaining and improving fundamental services for our most vulnerable population in Rhode Island as well. State Advocacy Days are critical opportunities for individuals and families to share their stories of how this disease affects them. These personal testimonies allow law makers to see firsthand the need for ongoing supports and services in Rhode Island.”

In addition to the human toll of the disease, care for Alzheimer’s - the country’s most expensive condition - will cost the nation $277 billion. By 2050, these costs could rise as high as $1.1 trillion.

These staggering numbers do not include unpaid care by friends and family valued at $232 billion a year or the more than $11.4 billion in increased healthcare costs for caregivers own health. State governments are increasingly on the front lines in addressing the Alzheimer’s crisis, the care and support needs of families facing the disease and its impact on local economies.

Interested in attending Advocacy Day and having your voice heard? Would your company like to have a vendor table? Contact Eric Creamer at ercreamer@alz.org to sign up.

CURRENT ADVOCACY OPENINGS

Congressional Team Members, Advocates and State Champions

Contact Eric Creamer at ercreamer@alz.org for more information
Congress passes BOLD Act funding for Alzheimer's

The Alzheimer’s Association and the Alzheimer’s Impact Movement (AIM) are celebrating the passage of the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act (S. 2076/H.R. 4256). Signed into law before the end of 2018, the bill will enhance and improve our nation’s public health response to the Alzheimer’s crisis, and further demonstrates that Congress remains fully committed to the fight to end Alzheimer’s.

Developed in close partnership between sponsors, the Alzheimer's Association and AIM, the bill quickly developed enormous bipartisan support. More than half of the 115th Congress — 58 Senators and 256 Representatives — cosponsored the bill. The bill unanimously passed in the Senate on December 12 and passed in the House 361-3 on December 19.

All four members of Rhode Island’s Congressional delegation, Rep. Langevin and Cicilline and Sen. Reed and Whitehouse, supported the bill.

“The passage of the BOLD Infrastructure for Alzheimer’s Act is an important step to address the growing Alzheimer’s public health crisis,” said Harry Johns, Alzheimer’s Association and AIM President and CEO. “We are thankful to the bill's bipartisan sponsors for their continued dedication and work to implement policies to improve the lives of all of those impacted by this devastating disease.”

The BOLD Infrastructure for Alzheimer’s Act will establish Alzheimer’s Centers of Excellence in communities around the country to expand and promote effective Alzheimer's interventions, and issue funding to state and local public health departments to promote cognitive health, risk reduction, early detection and diagnosis, and the needs of caregivers. Critically, the BOLD Infrastructure for Alzheimer’s Act will also increase collection, analysis and timely reporting of data on cognitive decline and caregiving to inform future public health actions.

Today more than 5 million Americans are living with the disease and by 2050 this number is projected to rise to nearly 14 million. Alzheimer's is the most expensive disease in the country, costing an estimated $277 billion — including $186 billion in direct costs to Medicare and Medicaid — in 2018.

“Today is an historic day for the millions of families affected by Alzheimer’s disease now that the BOLD Infrastructure for Alzheimer’s Act has been signed into law,” said Alzheimer’s Association Chief Public Policy Officer, Robert Egge. “Thanks to all the elected officials who championed this legislation, the country will now be better able to fight this devastating disease as we continue to work towards our vision of a world without Alzheimer’s.”

The Alzheimer’s Impact Movement (AIM) is the advocacy arm of the Alzheimer’s Association. AIM works to develop and advance policies to overcome Alzheimer’s disease through increased investment in research, enhanced care and improved support.

Eric Creamer joins Staff

Please welcome Eric Creamer, the new Director of Public Policy and Media Relations for the Alzheimer’s Association in Rhode Island. Eric formerly was the Executive Director for Mothers Against Drunk Driving in Rhode Island for the last four years, and spent 10 years prior as a Senior Service Area Director with the Narragansett Council, Boy Scouts in Rhode Island. He has a degree in journalism from Northeastern University and was a reporter with the Westerly Sun and Brockton Enterprise.
The Alzheimer's Association AIM Advocacy Forum is the nation's premier Alzheimer's disease Advocacy event. The forum is an annual opportunity for Alzheimer's advocates from across the country to directly appeal to their members of Congress about Alzheimer's disease in Washington, D.C. Join more than 1,000 advocates to advocate for research and care and support services. Because of our advocates' support we've had three consecutive years of historic funding increases at the National Institutes of Health for Alzheimer's disease research funding. It's where you need to be to continue playing a crucial role in the fight against the disease. Join us March 31-April 2, 2019!

To register visit alz.org/forum. For questions please contact Eric Creamer at ercreamer@alz.org or 401.421.0008.
**CVS Cares for Caregivers During the Holidays**

Right before Christmas 2018, staff of the RI Chapter of the Alzheimer’s Association spent the afternoon at CVS World Headquarters in Woonsocket, working to stuff holiday gift bags for caregivers of those affected by Alzheimer’s disease or dementia. Bags filled with comfort aids such as lotion, tea, essential oils, and music cd's were packed and readied to be delivered to caregivers around the state. Two hundred bags made their way to support groups, adult day centers and doctor's offices to be dispersed to primary caregivers. Kevin Hourican, President of CVS Pharmacies, the CVS Charity Classic Team and sponsors of the CVS Charity Classic all wrote cards of support and encouragement to those who provide countless hours of care to their loved ones.

"As we thought about doing a community service project to support the Alzheimer’s Association, we knew we wanted to focus our efforts on supporting the millions of caregivers caring for a loved one with Alzheimer's or dementia. We know that they are faced with a multitude of emotions and responsibilities that can often impact their own well-being," said Kevin Hourican, President, CVS Pharmacy. "Our team at CVS Health found it truly meaningful to be able to put together care packages including much-needed support tools for caregivers.

As my mother battled Alzheimer's, I know the items in our care packages will be very useful in helping caregivers take care of the ones they love suffering with the disease. For example, our care package included soothing music as we know that music is a calming force to many suffering with Alzheimer's or dementia. We appreciate all of the work the Alzheimer's Association is doing to support caregivers and the inspiring work they are doing to help find a cure."

The RI Chapter thanks Kevin Hourican and all members of the CVS community for their dedication and recognition of the heroes of Alzheimer’s disease and dementia.

**An Evening of Art As Love and Light**

The 5th Annual Driftwood Alzheimer’s Fundraiser to benefit the RI chapter of the Alzheimer's Association and the memory and aging program at Butler Hospital was held in November and featured a program of art, music and dance to raise money and awareness. Sponsored by Planet Fitness, the event was headlined by a live painting performance by renowned artist Paul Coté accompanied by the music of DJ Chahkram and the State Ballet of RI.

The event included a performance by indie rock band The Sound Of Gravity, recorded live for a future album release with proceeds benefiting both organizations.
The Longest Day is the day with the most light — the summer solstice. On June 21, thousands of participants from across the world will come together to fight the darkness of Alzheimer’s through an activity of their choice.

Together, they use their creativity and passion to raise funds and awareness for the care, support and research efforts of the Alzheimer’s Association.

One local girl, in recognition of her grandfather’s Alzheimer’s journey, chose to participate in The Longest Day in December. Sarah Greenberg a fourth grade student at Narragansett Elementary School, used her “Genius Hour” to plan, solicit and run a bake sale at the school.

She advertised the sale, asked her classmates to help bake and sold the sweet treats in the school’s faculty lounge. For all her work, she was able to raise over $200 for care, support and research for those affected by the disease.

With a visit from Kate Spinella, Development Director of the RI Chapter, the students were able to learn about the disease and ask questions about the work of the Alzheimer’s Association. Sarah’s dedication was able to raise funds for The Longest Day, and while at the same time raising the awareness of her classmates and teachers.
ALL ABOUT THE LONGEST DAY

The Longest Day® is the day with the most light — the summer solstice. On June 21, thousands of participants from across the world come together to fight the darkness of Alzheimer’s through an activity of their choice. Together, they use their creativity and passion to raise funds and awareness for the care, support and research efforts of the Alzheimer’s Association.

HOW TO PARTICIPATE

It’s easy — choose an activity you like to do and turn it into a fundraiser to fight Alzheimer’s! Follow the steps below.

1. **Select an activity you love at alz.org/thelongestday.**

   Any activity can be a fundraiser for The Longest Day:

   - If you’re a talented baker, invite friends and family to create desserts with you. Then host a bake sale and donate the proceeds as your fundraiser.
   - If you like to golf, host a tournament and ask for donations in lieu of an entry fee.
   - Host a BBQ and ask friends and family for a donation in exchange for a delicious meal.
   - Raise extra funds by adding a silent auction, challenge or competition to your activity. You can even ask for donations instead of birthday gifts!

2. **Start raising funds now.**

   To advance critically needed research and provide care and support, each participant is asked to raise funds for the Alzheimer’s Association. Start fundraising early and you’ll see your total skyrocket. We’re here to help with tools, tips and advice to make fundraising easy.

3. **Ask others to join you by:**

   - **Making a donation** — Ask friends and family to support you and get active on social media. Create a Facebook Fundraiser in your online Participant Center or share your fundraising page link on Twitter, Instagram and LinkedIn.
   - **Fundraising with you** — Use the prewritten emails in your Participant Center to invite friends, family and coworkers to sign up for your team.
   - **Attending your event or activity** — Invite your community to join you for The Longest Day.

Register now at alz.org/thelongestday.
WHERE DEMENTIA SCIENCE AND CAREERS ADVANCE

JULY 14-18
LOS ANGELES, U.S.

Register for Alzheimer's Association International Conference ®
The Global Forum to Advance Dementia Science

Join us for the Alzheimer’s Association International Conference® (AAIC®) 2019, the largest international meeting dedicated to advancing dementia science. From July 14-18 in Los Angeles, U.S., AAIC will offer over 100 sessions and 550 podium presentations focusing on basic science, emerging research, innovative practice techniques, imaging, technology and more. Learn new findings and breakthroughs while networking with the world’s leading dementia scientists. Register at alz.org/AAIC
Join the fight for Alzheimer's first survivor in Rhode Island this September. At the Alzheimer's Association Walk to End Alzheimer's®, people carry flowers representing their connection to Alzheimer's - a disease that currently has no cure. But what if one day there was a flower for Alzheimer's first survivor? What if there were millions of them? Help make that beautiful day happen by joining us for the world's largest fundraiser to fight the disease.

**EVERY DOLLAR COUNTS**

Join the fight for Alzheimer's first survivor in Rhode Island this September. At the Alzheimer's Association Walk to End Alzheimer's®, people carry flowers representing their connection to Alzheimer's - a disease that currently has no cure. But what if one day there was a flower for Alzheimer's first survivor? What if there were millions of them? Help make that beautiful day happen by joining us for the world's largest fundraiser to fight the disease.

**Where does the money go?**

We provide care and support for all those facing Alzheimer's across Rhode Island utilizing donated funds to offer:

- A free, nationwide, 24/7 Helpline 800.272.3900 staffed by specialists who provide support, offer information and lists of resources near you
- Support groups for care partners and those diagnosed with dementia to provide a local network of help and on-line connections through ALZconnected.org, a free message board service that builds relationship across the country.

We advocate for the needs and rights of people impacted by Alzheimer's. The Association is the leading voice for Alzheimer's advocacy in the world, advancing public policy that improves the lives of those living with dementia and their care partners.

We educate and raise awareness to grow understanding about the disease. To increase knowledge and support those facing dementia, your fundraising provides:

- Free educational workshops and programs about the 10 warning signs of Alzheimer's, living with the disease, caregiving at every stage, and healthy lifestyle choices
- A website - alz.org - that includes hundreds of pages of information in a variety of languages

We drive research toward treatment, prevention, and ultimately, a cure. As the world's largest nonprofit funder of Alzheimer's research, the Association invests your fundraising resources in innovative projects that hold the most potential to alter the trajectory of the disease.

Our team can also help build and motivate your Walk team, with suggestions for fundraisers, marketing materials to share with friends, family and co-workers. Visit alz.org/ri/walk or call 800.272.3900 to get walking!

Your support of the Walk to End Alzheimer's through registration for local Walks and your fundraising put us one step closer to a world without Alzheimer's. We can start or renew your Walk team in a matter of minutes.

Contact Bella Garcia to start your team at 1-800-272-3900 or at agarcia@alz.org
VOLUNTEER WITH US!

Volunteers are needed to provide ongoing support for our mission, facilitate and lead programs, join event and other planning committees. Please send the following application or call 1-800-272-3900 for more information on how to get involved.

Volunteer for the Alzheimer's Association and be part of an incredible team! Areas of need include Education and other Programs, Special Events, Advocacy, Media and Communications. Ready to join and see how your efforts will make a meaningful impact? Contact Jennifer Atkinson at jratkinson@alz.org or 1-800-272-3900.
Rhode Island Chapter
VOLUNTEER APPLICATION

SECTION 1: Personal Information
Please print clearly

Name_________________________ Home Phone ( )

Address:______________________ State______ Zip_____________ Fax ( )

City_________________________ State________ Zip_________ Fax ( )

Place of Work/School_________________________ Position/Year In School ______

Email Address (print clearly)_________________________

Primary Language_________________________ Best time to call/Preferred number_________________________

I am seeking community service hours or an internship/practicum: Yes ☐ No ☐

Program/Degree_________________________ Hours Needed_________________________ By when_________________________

Connection to Alzheimer's disease (check all that apply)
☐ Family Member ☐ Caregiver ☐ Other ______
☐ Friend of person with AD ☐ Community Supporter
☐ Student interested in AD ☐ Healthcare Professional

Emergency Contact (required)
Name:_________________________ Relationship:_________________________

Phone: ( )_________________________ Email:_________________________

Please indicate which days and hours you are available to volunteer:

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www.alz.org/ri
Rhode Island Chapter
245 Waterman Street, Suite 306
Providence, RI 02906

24/7 Helpline
For more information call
1-800-272-3900
or visit www.alz.org/ri

Current Resident Or: