

ALZHEIMER'S DISEASE

3
FACTS

THAT WILL
EMPOWER YOU
TO JOIN THE
MOVEMENT



ACT TODAY TO GIVE HOPE FOR TOMORROW

Actor and advocate David Hyde Pierce discusses his family's experience and how we can join together to confront the disease

PHOTO: ALZHEIMER'S ASSOCIATION

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CHALLENGES

You may ask, “What can I do against this onslaught?”
Everyone has a role to play. Every voice contributes to better care and progress towards a cure.

A world without Alzheimer’s

I can see a future without Alzheimer’s disease. And I need your support to achieve it. I am an honorary Board member of the Alzheimer’s Association—the leading voluntary health organization committed to Alzheimer’s care, support and research. We’re working to fulfill our vision of a world without Alzheimer’s.

As many as 5.4 million Americans have Alzheimer’s, and 10 million more will develop the disease by mid-century. Alzheimer’s costs the U.S. economy more than \$183 Billion annually, and by 2050 that number is expected to exceed \$1 trillion. As deaths caused by other major diseases have declined, Alzheimer’s deaths have increased; it is now the sixth-leading cause of death in the United States.

You may ask, “What can I do against this onslaught?” Everyone has a role to play. Every voice contributes to better care and progress towards a cure.

My own effort started 15 years ago with an appearance on “Celebrity Jeopardy” to raise money for the cause; then

the Alzheimer’s Association recruited me to join their Walk to End Alzheimer’s™. I’ve gone to Washington, DC and testified for a stronger government commitment for Alzheimer’s research. Now I’m a member of the advisory council for the National Alzheimer’s Project, which is charged with helping develop a national Alzheimer’s plan.

I’m calling on you to do whatever you can to end Alzheimer’s disease. In your way. In your community.

Read the stories in this special section and marvel at the lengths people will go to raise awareness and money for Alzheimer’s. Climbing mountains, jumping out of airplanes, running great distances, creating new events, and making their voices heard. These are ordinary people whose passion for defeating Alzheimer’s disease stimulates creativity and action, in themselves and others.

Awareness: A priority

I have seen people with Alzheimer’s stand before our elected members of Congress to tell them of the



David Hyde Pierce
Actor and Alzheimer’s Association
National Board Member
PHOTO: ALZHEIMER’S ASSOCIATION

unrelenting realities of Alzheimer’s—and I’ve seen those Congress members moved to take action. I’ve met caregivers from age 18 to 80 who labor around the clock to care for their family member with dementia—and I’ve seen those same caregivers and their families and neighbors dance, walk, climb, bake, pray, write, and speak to raise awareness and funds for the fight against Alzheimer’s disease. These are true heroes.

When we work together, Americans fix problems. With the National Alzheimer’s Project, we have a great opportunity: we can confront this disease and

make the same kind of progress that we’ve made in heart disease, HIV/AIDS, and cancer.

A call to action

My grandfather and my dad had Alzheimer’s and dementia, so my family knows first hand what a terrible disease it is. But you don’t have to have someone with Alzheimer’s in your family to be a part of this movement. It’s a public health crisis with far reaching consequences—on our healthcare system, our nation’s fiscal health and our citizens. The epidemic is upon us. We need everyone to join this fight. We need you.

Acting today gives us hope for tomorrow. I know I can count on you.

David Hyde Pierce earned four Emmy Awards for his portrayal of Niles Crane on the TV series “Frasier,” and has extensive credits on Broadway and in film. He’s been an Alzheimer’s Association National Board Member since 1999. In 2010, he was awarded the Tony Awards’ Isabelle Stevenson Award for his work with the Association.

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Hope on the horizon

- **Question:** How can caregivers and patients get involved in treatment development and research?
■ **Answer:** Clinical trials.

As a psychiatric nurse practitioner, **Dr. Denise Canchola** from Pompano Beach, Fla., knows that research studies are the best bet for new and better treatments—and for holding onto hope.

When Denise’s mother, Gabriela, was diagnosed with Alzheimer’s disease in 2010, she began to look for research study information. She found Alzheimer’s Association TrialMatch™, a free matching service

that connects individuals living with Alzheimer’s, caregivers, and healthy volunteers with current clinical trials.

“Alzheimer’s Association TrialMatch is easy to use and the telephone specialists are incredibly responsive,” says Canchola.

Gabriela lives in San Antonio, Texas. Located hundreds of miles apart, Canchola and her family used TrialMatch to find a huge array of Alzheimer’s clinical studies. Currently, Alzheimer’s Association TrialMatch lists more than 130 research studies with 545 trial sites nationwide.

Canchola adds, “I was concerned because I live out of state, but the Tri-

alMatch specialist remained in touch with our family throughout this whole process.”

A family affair

Though her seven siblings usually rely on her professional expertise, Canchola had a difficult time getting them on board for enrolling their mother in a clinical trial. She pointed them to alz.org to learn more about Alzheimer’s, including clinical trials.

They learned that clinical trials present an opportunity for people to play a more active role in treatment and contribute to scientific discovery. In short, clinical trials offer hope.

Since its debut in July 2010, TrialMatch has matched more than 2,500 people to Alzheimer’s clinical trials based on their diagnosis, preferences and location. The internet (alz.org/trialmatch) and phone-based (800-272-3900) service provides comprehensive clinical trial information.

“Clinical trials give us something to do and hold on to,” says Canchola. “I can see the difference in my mother’s attitude and the attitudes of my siblings. We’re not letting Alzheimer’s take our mother without putting up a fight.”

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WE RECOMMEND



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Join the cause:
Speak up for the needs of Alzheimer’s patients and caregivers

“Emotionally, it was devastating to see his mind, personality and abilities slip away week by week, right in front of my eyes.”

Ask the experts

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Industry leaders weigh in.

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Do you know someone who has memory loss?
Is someone you love struggling to stay independent?

EASTER SEALS SOUTH FLORIDA OFFERS HELP, HOPE AND ANSWERS TO FAMILIES AND THEIR OLDER LOVED ONES.

“At Easter Seals, we believe that home and community-based services such as in-home care and adult day services are an important option for families -- as a lifestyle choice and a financial reality. We offer families options with services and supports for older adults and families living with Alzheimer’s.” This is how Angela Aracena, vice president, Program Services, Easter Seals South Florida talks about the services that Easter Seals South Florida provides for area families.

Angela Aracena is an innovator, a collaborator, a teacher, and a passionate advocate for older adults at Easter Seals South Florida. Her colleagues hold her in the highest regard and Easter Seals honored her with its 2011 Lowenkron Innovation Award. As a physician, Aracena began her career in rural areas of her native Dominican Republic before coming to South Florida to develop services for older adults and their families.

Today, Easter Seals South Florida is among the best in the emerging field of Adult Day Services for people with Alzheimer’s disease and other related disorders. Aracena has led the growth of adult day services from one center with 25 participants to three centers – in Miami, Hialeah and Broward County -- serving almost 300 older adults on a daily basis. And, with her team, she has developed Easter Seals Memory Gym, incorporating the latest research on managing early memory loss by creating innovative opportunities for people to learn new skills.

Knowing the needs of families, Easter Seals South Florida also has developed a number of programs including in-home services to assist caregivers caring for elders at home and to provide culturally-sensitive services in area communities for the aging population.



INSIGHT

FACT

1

ALZHEIMER'S COSTS THE U.S. ECONOMY MORE THAN \$183 BILLION ANNUALLY

Question: Is there a way to prepare myself and my family if we end up facing Alzheimer's disease?
Answer: Preparing your financials is the first step.

Financing for the future

People with Alzheimer's—a progressive, degenerative brain disease—will need escalating levels of medical and personal care, attention so they avoid getting lost or hurt, and eventually, assistance with even the most basic aspects of living.

Most of this care is provided by family members, friends and community-based organizations. However, these voluntary services may not be sufficient or available, particularly as care needs approach 24-hours-a-day and include physically intense and skilled services.

In highly populated areas, there are usually a variety of supportive care services available. In less densely populated communities, options may be limited. Sources of care include: nurses, nurses' aides, social workers, nutritionists, and speech and physical therapists,



among others. Services may be available independently or through a wide array of social service agencies. Some care services are included in residential care options, such as assisted living facilities and nursing homes, but even in these settings supplemental assistance may be needed.

Understanding just what care services are covered by health insurance, including Medicare, can be confusing. For example:

■ If the absence of sufficient care results in a hospitalization, then supportive care needs will

be paid for by health insurance.

■ If the hospital stay extends beyond three days, then Medicare will pay for a substantial amount of supportive care, as long as it is bundled with other skilled and rehabilitative care. However, this coverage will be limited in scope and duration.

Planning ahead

Long-term care insurance may help, but the type of care most people need, particularly in the early stages of Alzheimer's, is not covered by this insurance. Licensed services are only covered once your ability to care for yourself is so limited that you could not function for a

day without support. The inability to prepare a meal or manage your medications is not sufficient, but the inability to feed yourself or use the toilet is.

Reassurance with insurance

Limitations in at least two necessary activities of daily living, or being so cognitively impaired that you need constant supervision, will enable you to use long-term care insurance benefits. The benefit amount is based on what you chose when you purchased the insurance policy. For example, if you purchased a daily benefit of \$150, then your insurance will only cover up

to \$150 of the care that you use in a day.

The bigger picture

As a result, the person needing care over a long period of time will pay directly for most of that care. Current (usually retirement) income and past savings will be the primary source, but some will borrow from the equity in their home. Once financial resources are sufficiently depleted, or when costs substantially exceed income, you may be eligible to apply for assistance from your state Medicaid program. Eligibility is based on the patient's age, level of functional dependency, remaining savings and income. All state Medicaid programs cover care in a nursing facility; some states have established programs for Medicaid-covered assistance in other settings.

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"In highly populated areas, there are usually a variety of supportive care services available."



It's just as easy to protect against the high cost of long-term care.

The need for long-term care may not be the first thing you think of when you think of protecting your family, but preparing for it is easy. To learn about long-term care insurance, visit northwesternmutual.com.

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DON'T MISS!

Funding the fight

As the Alzheimer's disease epidemic grows, Americans are taking action by fundraising for the cause. You can act in your community with these fun ideas:

■ Join the Alzheimer's Association Walk to End Alzheimer's™, the nation's largest event to raise funds for Alzheimer's. Find an event near you at alz.org/walk.

■ First-time walker, Hye Kim, collected more than \$1,600 for the Washington, D.C. area walk by asking friends and family to skip their daily latte and make a donation instead.

■ Host a bake sale, garage sale or car wash. These tried-but-true fundraising ideas are popular—because they work! Donate the proceeds—and let your buyers know it.

■ Get “Casual for the Cause” at work. Sell passes to dress down for the day for a donation to the Alzheimer's Association. Learn more at actionalz.org.

■ Host a dinner party; ask your guests to donate what they would have spent at a restaurant.

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ALZHEIMER'S ADVOCATE TURNS EXPERIENCE INTO ACTION

Alzheimer's disease is a life-changing experience for everyone it affects. In Susan Crowson's case, it was more than that—it was a call to action.

Crowson's father, Warner, was diagnosed with Alzheimer's in 2007. She became his primary caregiver when her mother, Geraldine, passed away that same year. Crowson says caring for Warner, who passed away in February, was a great joy, as well as the most difficult thing she's ever done.

“Alzheimer's caregiving was physically demanding because it was 24-7,” Crowson said. “Emotionally, it was devastating to see his mind, personality and abilities slip away week by week, right in front of my eyes.”

Her life permanently altered, Crowson didn't retreat. Instead, she became an Alzheimer's Association Ambassador—using her passion and personal experience to educate Rep. Roscoe Bartlett (R-Md.) and his staff on the effects of this heartbreaking disease on families.

Crowson was instrumental in the Alzheimer's Association's public input session in Frederick, Maryland on Alzheimer's Action Day, September 21, 2011. It was one of more than 130 events held across the country to gather insights on what the public feels must be included in a National Alzheimer's Plan, currently being developed as part of the



National Alzheimer's Project Act (NAPA). The insights and perspectives gathered at these sessions culminated in the Association's report, “Alzheimer's from the Frontlines: Challenges a National Alzheimer's Plan Must Address”, released in November.

An economic impact

Ten key challenges emerged out of the public input process. Among them are: the need to increase awareness of the impact of Alzheimer's, develop more effective treatments faster, provide better care throughout the disease, ensure better support for caregivers, and reduce disparities that exist



among diverse communities.


Crowson was a featured speaker at the local Frederick event, presenting information about projected future costs and the devastating impact of Alzheimer's on the U.S. economy and healthcare system. She challenged attendees to become more educated about Alzheimer's and to demand that their elected officials make Alzheimer's a national priority.

“Each person (who spoke) was deeply sincere and thoughtful about asking for more helpful services, for modifications to Medicare and Medicaid, and respite for caregivers,” she said. “NAPA input is the ‘voice of the

people.’ I believe it will have a significant impact because of the quality of input and the volume of response from communities across the nation. This is democracy in action.”

To learn about NAPA and to read “Alzheimer's from the Frontlines”, visit alz.org/napa.


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INSIGHT

	Steve Sperka Northwestern Mutual vice president of long-term care		Richard S. Isaacson, MD Associate Professor of Clinical Neurology, U. Miami Miller School of Medicine		Marc E. Agronin, MD Medical Director for Mental Health and Clinical Research, Miami Jewish Health Systems	
Question 1: What are the first measures you should take if someone you know has been diagnosed with Alzheimer's disease?	The first step comes long before the diagnosis: developing a plan. We encourage all Americans to meet with a financial professional and address the potential risks to their financial security, such as Alzheimer's. As health care costs rise and lifespan increases, it's important to think ahead and start planning for future long-term care needs. Have you considered how you might pay for 24/7 care, if that became necessary?		Get educated —get informed. There are so many new therapies for Alzheimer's Disease. See a qualified medical professional, and build a network of support around your loved one who was diagnosed. It is imperative to establish routine care with a physician, live a healthy lifestyle, and learn about all treatment options.		Someone with suspected or known Alzheimer's disease must be seen by a specialist, whether a geriatric psychiatrist or neurologist, who can make a correct diagnosis, provide sensible treatment, and help to manage the associated psychiatric problems so common to Alzheimer's disease.	
Question 2: What do you think is the most common misconception regarding Alzheimer's disease today?	We see it all the time—the “it can't happen to me” syndrome. Whether injury or illness, most Americans feel invincible, and neglect to prepare for the unexpected. The Alzheimer's Association reports that by 2050 the disease will impact up to 16 million U.S. families directly, and millions more indirectly. Those numbers could include any of us.		That there is “nothing you can do” or that the only treatments available are FDA-approved drugs. I can't stress enough the importance of a comprehensive, multi-model approach. The non-drug approaches are as important, such as physical exercise, mental exercise, and music therapy for memory.		Many people assume that individuals with Alzheimer's disease have no capacity to enjoy life or meaningful pursuits because of memory impairment. But we know the brain is capable of so many things even in the face of Alzheimer's disease—humor, creativity, sensory enjoyment, affection, and others.	
Question 3: How do you recommend everyday individuals get involved in the fight to find a cure?	While I'm not a medical expert, I would encourage all individuals to educate themselves about the disease and the impact it has on families—both emotionally and financially. Awareness is the first line of defense.		There are a variety of organizations that hold fundraising activities toward finding a cure. In 2011, the National Alzheimer's Project Act was signed into law, which will help create a coordinated national strategy against Alzheimer's Disease. Officials creating our national Alzheimer's Disease plan need to hear from as many advocates as possible.		Volunteer at a nursing home or day-care program. Help out a loved one, friend or neighbor who is a caregiver for someone with Alzheimer's disease. These are two areas in tremendous need.	

FACT

3

AS MANY AS 5.4 MILLION AMERICANS HAVE ALZHEIMER'S DISEASE



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