

# ALOIS CONNECTOR

## SOCIETY

The Alois Society Connector is published exclusively for our valued Alois Society members by the Alzheimer's Association®, the world's leading voluntary

health organization in Alzheimer's care, support and research. Thanks to the exceptional financial leadership of our Alois Society members, the Association is making significant progress in our mission to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Thank you again for your support of the Alzheimer's Association.

## member leads the longest day team past fundraising goal; drives awareness



Matt Steele with his wife Margie

Margie, Matt Steele's wife of 30 years, started showing symptoms of Alzheimer's at age 50. Three years later, they met with her primary care physician who ran down the list of warning signs—memory loss that disrupts daily life, difficulty completing familiar tasks, confusion with

time or place, and so on—but he said, “I'm sure it's not Alzheimer's. You're way too young for that.” But it was younger-onset Alzheimer's. Now at age 57, Margie is in severe decline.

Accepting Margie's condition and managing the day-to-day challenges often feels overwhelming, so Matt considered how he might support the Alzheimer's Association beyond his Alois Society membership. He and their three children decided to participate in and raise money for the Association's *The Longest Day*® on June 21. Their team, called “Minds Over Matter,” consisted of a core group of 12 people doing a range of activities from running and walking to skateboarding and cycling. “I think for all of us, it's kind of empowering, a small

way to do something about what feels like a hopeless situation,” Matt said.

Surpassing their initial fundraising goal of \$5,000 fairly easily, the team raised the bar to \$15,000 and soon exceeded that. They reached out by email, Facebook, and word of mouth. We were looking for quantity as well as quality, Matt said. “Even if someone gives \$20, it's not so much the money as the awareness aspect... (However,) we were aiming to be the number one fundraising team.”

Margie's family has been devastated by the disease, further motivating Matt's family to join the fight. Margie's mother died of Alzheimer's in 2010 and her sister, now in her early 50s, was just diagnosed.

“It's one of the things I want to do with my life—get involved with raising awareness, if it'll help other people.”

Matt reflects on how energetic Margie once was; how she was driven to help others. Twenty years ago, she founded the food pantry in the Boston suburb where they live, and she

## WHAT YOU'LL FIND INSIDE

### PAGE 2

- Walk to reclaim the future
- Latest Facts & Figures report points to Alzheimer's epidemic

### PAGE 3

- Leading researcher optimistic on progress
- Celebrating 25 years of progress in dementia science

### PAGE 4

- Online Caregiver Center provides essential resources, support

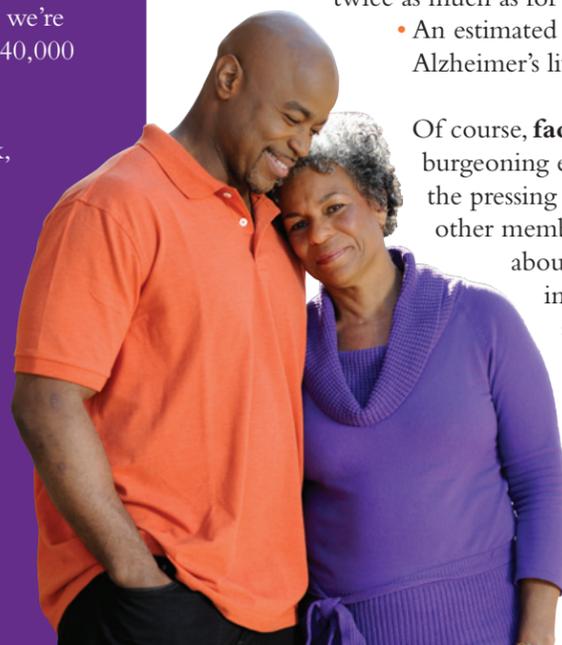
## walk to reclaim the future



You can make a difference in our fight to reclaim the future—a future free from Alzheimer's. The Alzheimer's Association **Walk to End Alzheimer's®** is the nation's largest event to raise awareness and funds for Alzheimer's care, support and research. Held annually in more than 650 communities nationwide, this inspiring event unites people in a display of strength and dedication to overcome this devastating disease.

Last year, participants raised more than \$52 million to help change the course of this disease. There's a long road ahead, and this year we're hoping to register more than 40,000 teams.

When you participate in Walk, your fundraising dollars fuel our mission-related initiatives of care, support and research. Your actions, both through fundraising and participating in the event, help to enhance Alzheimer's awareness in your community. Get involved and sign up your team today! Learn more at [alz.org/walk](http://alz.org/walk).



## latest facts & figures report points to alzheimer's epidemic

The 2013 *Alzheimer's Association Alzheimer's Disease Facts and Figures* report reveals startling figures about the growth of Alzheimer's and the emotional and financial burden the disease places on individuals, caregivers, government and the nation's health care system.

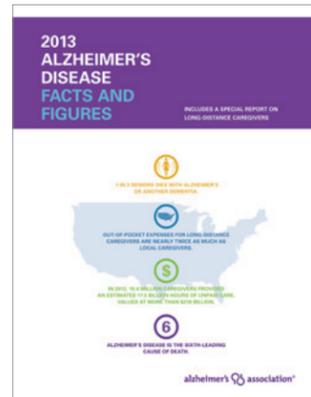
According to the report, Alzheimer's is the sixth-leading cause of death in the United States and is the only one in the top 10 that cannot be prevented, cured or even slowed. Someone develops the disease every 68 seconds. Unless significant resources are invested and progress toward improved treatments and cures is made, someone will develop the disease every 33 seconds by mid-century.

Other statistics included in the report are just as alarming:

- In 2012, there were more than 15 million caregivers of people with Alzheimer's and other dementias who provided over 17 billion hours of unpaid care.
- In 2013, Alzheimer's will cost the nation \$203 billion; this number is expected to rise to \$1.2 trillion by 2050. In support of these alarming facts and figures is the recent New England Journal of Medicine/RAND article indicating that direct healthcare costs for Alzheimer's and other dementias are now greater than heart disease or cancer. It is the costliest disease in the United States and increasing.
- In 2013, an estimated 450,000 people will die with Alzheimer's disease.
- Out-of-pocket expenses for long-distance caregivers are nearly twice as much as for local caregivers.
  - An estimated 25 percent of individuals with Alzheimer's living in the community live alone.

Of course, **facts and figures** like these underscore the burgeoning epidemic that the nation now faces—and the pressing need for continued support from you and other members of the Alois Society. To learn more about the increasing prevalence of Alzheimer's in every state, by gender, and the challenges specific to long-distance caregivers, go to [alz.org/facts](http://alz.org/facts), where you can download and read the 2013 *Alzheimer's Disease Facts and Figures* report in its entirety.

Please take the time to share our statistical resources for U.S. data related to Alzheimer's disease with a friend.



## leading researcher optimistic on progress



Early in his career, Dr. Dave Morgan worked in neuroscience, as he was fascinated by the learning process and the brain. That led him to focus on the science of aging just as scientific understanding of Alzheimer's was becoming an "earnest scientific discipline," he said. Today, he believes that research is moving forward exponentially. However, he cautioned that making such progress relies on two factors: funding and focus: "We don't need miracles to prevent this disease. What we need are the resources and the hard work to do these challenging and expensive clinical trials."

One of the field's top experts, Dr.

Morgan has received multiple grants from the Alzheimer's Association and other organizations like the National Institutes of Health. In his role as CEO and Director of the Byrd Alzheimer's Institute at the University of South Florida, he leads basic and translational Alzheimer's research that has produced several promising findings. This summer marks the start of a series of multi-year studies focusing on preventing Alzheimer's or delaying its onset in those who are at greatest risk. "I'm pretty confident that...one or more of the approaches we're taking will be effective," Dr. Morgan said.

Just who has the potential to develop the disease? During the last 20 years, scientists have reached consensus that the initiating factor for Alzheimer's is the accumulation of amyloid, a waxy, translucent substance consisting primarily of protein, and aging is the main cause. With a PET scan or a spinal tap, "we can detect amyloid in the brain, so we can identify those people who are at the greatest risk," Dr. Morgan said.

Having the ability to prevent Alzheimer's disease in the near

future doesn't mean people won't develop it. Not everyone will undergo the tests necessary to discover they're at risk, and not everyone will take the medicines available to them. But the potential number who will be able to prevent or delay the disease's onset is staggering. Today, the death rate from heart disease, prostate cancer, breast cancer, HIV and stroke is declining, but the number of Alzheimer's deaths is rising—increasing 68 percent between 2000 and 2010. If we make the kind of progress that Dr. Morgan envisions, Alzheimer's could indeed reverse its current course.

"We don't need miracles. We need resources."

The Alzheimer's Association has provided Dr. Morgan with critical research support. "The Association is effective at targeting grants toward work that can have more immediate impact," Dr. Morgan said. "The organization is willing to support exploratory studies that

(continued on page 4)

## celebrating 25 years of progress in dementia science

From its beginning in Las Vegas in 1988 to a record-breaking year in Paris in 2011, the Alzheimer's Association International Conference® is the world's largest annual gathering of the dementia research community.

Celebrating 25 years of discovery, progress and change at the AAIC® 2013 in Boston, United States, July 13–18, participants including researchers, clinicians, primary

care physicians and caregivers will examine where we have been—and where we are going—on the path to end the Alzheimer's epidemic. Sessions will focus on the latest research findings, advances in diagnostics and treatment, as well as the ways in which technology can positively impact care and support

As a way of commemorating this AAIC milestone and calling attention to the many highlights along the way, we've put together a special interactive timeline that we invite you to view at [alz.org/aaic](http://alz.org/aaic).

You can help advance research by participating in a clinical trial. Learn more at [alz.org/research](http://alz.org/research).

*(Member leads The Longest Day team past fundraising goal, continued from page 1)*

managed it until she became too ill to continue. In 2006, the town named her Citizen of the Year for her lifetime of community service. “She’s a wonderful person,” Matt said, but as the disease progressed, she became “less and less herself.”

Matt, an Alois Society member, said the Alzheimer’s Association has been an invaluable partner. “They’ve been the resource, giving me the big picture outline of what I should be doing.... I’ve called the helpline several times when I’ve needed an answer right away,” he said. Through his local chapter, he found a case worker to help in a number of ways, including recommending caregivers to provide respite.

“It’s really important that people have help. Then you’re able to get away and collect your thoughts, and when you come home, you’re ready to face it again,” he said.

## online caregiver center provides essential resources, support



If you’re a caregiver, we know you face many challenges. The day-to-day care you provide can be stressful, and you may need access to helpful resources—fast. The **Alzheimer’s and Dementia Caregiver Center** ([alz.org/care](http://alz.org/care)) is a “one-stop shop”

for tools, resources and information that caregivers need throughout the course of the disease.

The Caregiver Center provides information concerning the progress of the disease and how best to manage each stage, as well as insights into behavioral and physical changes that the individual with Alzheimer’s will likely experience and recommendations for activities that are appropriate.

From insurance to Medicare, a living will to guardianship, the online Caregiver Center will help you put financial and legal plans in place now. It will also help you find additional support from your local Alzheimer’s Association chapter, support groups, online message boards and e-learning workshops.

Plus, you’ll have the opportunity to join **ALZ Connected™** ([alzconnected.org](http://alzconnected.org)), a social networking community where people with Alzheimer’s, caregivers and others can share concerns and get advice. You’ll also be able to use **Alzheimer’s Navigator™** ([alzheimernavigator.org](http://alzheimernavigator.org)), an online assessment program that helps caregivers and people with dementia evaluate their needs and connect with local resources.

Visit the Alzheimer’s and Dementia Caregiver Center at [alz.org/care](http://alz.org/care).

*Margie Steele*

*(Leading researcher, continued from page 3)*

will lead to more comprehensive research. Federal funding is vital, but every contribution to the Alzheimer’s Association helps to advance the fight against a disease that’s reaching epidemic proportions.”

While there’s a tremendous amount to learn, Dr. Morgan is optimistic: “It’s been a fascinating period of time. There’s no doubt in my mind that progress has been made, and the pace has picked up. We’re on the cusp.”

Learn more about the latest discoveries and current research initiatives to develop a new generation of more effective treatments—and ultimately a cure—at [alz.org/research](http://alz.org/research). You can help advance research by creating a TrialMatch profile.

**ALOIS**  
SOCIETY  
alzheimer’s association

**Join the movement  
to end Alzheimer’s.**  
Visit [alz.org/AloisSociety](http://alz.org/AloisSociety)

ANAAM1401-ALOIS-NSLT