

# ALOIS SOCIETY CONNECTOR

## Our Community: Closing the Research Gap



Alzheimer's disease affects everyone, yet some groups with a higher incidence of Alzheimer's and other dementias have been under-represented in research studies. For instance, older African Americans are about twice as likely as whites to develop Alzheimer's, and older Hispanics about one and a half times. But knowledge about how best to deliver effective programs and services to these and other underserved populations may not be definitive.

What's more, traditional classifications of subgroups such as African

Americans, Hispanics or Latinos and American Indians and Alaska Natives don't begin to identify America's multifaceted populations.

**The Alzheimer's Association seeks to close that research gap by making it a priority of the 2014 International Research Grant program.**

Many underserved groups also encounter problems accessing services or information about Alzheimer's disease. In response, the Alzheimer's Association is working in local communities to increase awareness of the disease and the obstacles to service.

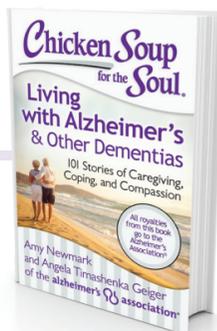
In summary, research pools will be expanded to reflect the diversity of America, also taking into account variables including:

- Socioeconomic status
- Values and beliefs
- Role of family and community
- Geographical and regional variation

By ensuring that critical research includes all of America, we can make new projects, programs and treatments as effective as possible.

## Another Serving of Chicken Soup

The Alzheimer's Association, in collaboration with the publishers of the Chicken Soup for the Soul series, introduces *Chicken Soup for the Soul: Living with Alzheimer's & Other Dementias*.



This collection gathers 101 stories that offer practical advice, encouragement, insight and support for people living with Alzheimer's or another dementia. The book is meant to raise awareness of the Alzheimer's epidemic and comfort those impacted by the disease.

The Alzheimer's Association will receive a portion of the proceeds for as long as the books are sold. Visit [shop.alz.org](http://shop.alz.org) to purchase a copy of the book.

*(Family Unites to Battle Alzheimer's cont'd from p.1)*

But the family gathered their strength and have become a unified force in the fight against Alzheimer's. In April, Nancy attended her fourth Alzheimer's Association Advocacy Forum in Washington, D.C., and she serves as the Alzheimer's Ambassador to Sen. Amy Klobuchar (D-Minn.), among other efforts.

Alisa is one of the founders of Blondes vs. Brunettes Twin Cities, a flag football fundraiser whose first event last fall raised a remarkable \$125,000 for the Alzheimer's Association. And Ryan co-chairs the advocacy committee of the Alzheimer's Association's Young Champions.

Nancy said the family is committed to doing their part to bring an end to Alzheimer's. She said she has been a member of the Alois Society since 2009 because "we need to find a cure."

## Family Unites to Battle Alzheimer's

Nancy Kiskis misses Sunday afternoons with her husband, Lenny. The two of them would stand side by side chopping vegetables and chatting. During the long Minnesota winters, they would make a different soup every week. "Sunday afternoons are hard for me now," Nancy said.

Eight years ago at age 56, Lenny was diagnosed with younger-onset Alzheimer's disease, and last September, he succumbed to it. "There were a lot of little signs, but never ever in our wildest dreams did we think it would be Alzheimer's," Nancy said, adding,

"we were devastated. When we got the news, I was crying so hard I couldn't catch my breath."

It took time, but eventually, she, Lenny and their children, Alisa and Ryan, rallied and decided to do everything in their power to fight this cruel disease — the sixth-leading cause of death in the United States.

**"This is an investment not only in the financial well-being of our country, but also in family and future generations,"**  
— Nancy Kiskis

Nancy became a member of the Alois Society because, as she put it, the urgency of this escalating national crisis called for as strong a response as she could muster. "This is an investment not only in the financial well-being of our country, but also in family and future generations," she said.

Nancy and Lenny were married 39 years, but about ten years ago, life began to change. Lenny was a



Back row: The Kiskis family. Front: Minnesota Twins manager Ron Gardenhire and team owner Carl Pohlad.

bank executive with Marquette Financial — one of the Pohlad Companies, which also owns the Minnesota Twins. He was struggling at work and told Nancy he was thinking about retiring. She was puzzled but she encouraged him to explore a career change. He replied, "I couldn't learn a new business."

That was a red flag, and the family became increasingly aware of his symptoms. The turning point came when Lenny gave Nancy a note from his boss, who compassionately urged Lenny to see a doctor. He did, and on June 30, 2005, he was diagnosed with Alzheimer's.

Carl Pohlad, CEO of the Pohlad Companies, told Nancy that Lenny "will always have a job here," and six weeks after Lenny's diagnosis, Pohlad invited the Kiskis family to join him in the owner's box at a Twins game. It was a bittersweet day because Lenny and Nancy had just told Ryan, Alisa and her husband Dan about the diagnosis.

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Join the movement to end Alzheimer's.

Visit [alz.org/AloisSociety](http://alz.org/AloisSociety)

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## Taking Steps to End Alzheimer's

Every step you take is a step toward hope in the 2014 Alzheimer's Association Walk to End Alzheimer's®.

Walk to End Alzheimer's is the world'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 calls on more than 400,000 participants of all ages and abilities to reclaim the future for millions.

There are many ways for you to show your support for this event. At [alz.org/walk](http://alz.org/walk) you can find a walk near you, register a team, or sponsor a team or a walker.

As a member of the Alois Society, you are invited to show your support in any way you choose. There is no fee to register, and the Alzheimer's Association provides free, easy-to-use tools and staff support to help all our teams and walkers reach their fundraising goals.

Take a step toward a world without Alzheimer's by visiting [alz.org/walk](http://alz.org/walk). The more we walk, the sooner we win the fight against this devastating disease.

## Public Policy Update:

### Alzheimer's Accountability Act

When Congress passed the landmark National Alzheimer's Project Act in 2010, the Department of Health and Human Services was tasked with producing a National Alzheimer's Plan and updating it each year.

This plan includes outcome-driven objectives, recommendations for priority actions, and coordination of all federally funded programs in Alzheimer's research, care and services, with the goal of effectively treating and preventing Alzheimer's by 2025.

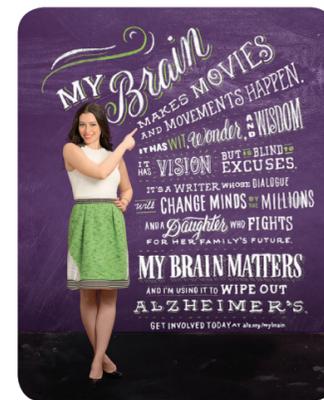
**One critical element has been missing from this plan, however: an annual projection of the level of funding necessary to reach this goal.**

That's why the Alzheimer's Association applauds four members of Congress for introducing the Alzheimer's Accountability Act (S. 2192/H.R. 4351). This legislation would require NIH to submit an annual research budget proposal directly to Congress and the President, specifying the resources needed to fully implement the National Alzheimer's Plan.

The Alzheimer's Accountability Act would not only be an accountability tool; it would also provide a detailed, scientific roadmap to achieving the goal of effectively treating and preventing Alzheimer's by 2025. We commend bill sponsors Rep. Brett Guthrie (R-KY), Rep. Paul Tonko (D-N.Y.), Sen. Ed Markey (D-Mass.), and Sen. Mike Crapo (R-Idaho) for taking action, and we encourage you to write to your representatives in Washington, D.C., and show your support for this important bipartisan initiative.



## Use Your Brain to Help Wipe Out Alzheimer's



Your brain matters. Now there's a way to celebrate it, share your thoughts and become part of an exciting community — a movement — at [mybrain.alz.org](http://mybrain.alz.org).

Just think: at only 3 pounds, your brain probably weighs less than a purse, yet it is your most powerful organ — controlling your thinking, breathing and movement and giving you your extraordinary sense of passion, humor and purpose.

**But women are at the epicenter of the Alzheimer's epidemic.**

According to the latest data released by the Alzheimer's Association, a woman's lifetime risk of developing Alzheimer's at age 65 is 1 in 6, compared with nearly 1 in 11 for a man.

What's more, women in their 60's are about twice as likely to develop Alzheimer's over the rest of their lives as they are to develop breast cancer.

Women are also more likely to become full-time caregivers to people with Alzheimer's disease, including their spouses, parents, sisters and friends. It is clear that women are at the epicenter of this crisis.

**The Alzheimer's Association invites all women to join this new movement that emphasizes celebrating and protecting your brain.**

Visit [mybrain.alz.org](http://mybrain.alz.org) today and tell the world, in 130 characters or less, why your brain matters. You can also learn more about women and Alzheimer's disease, get the 10 signs that are key to early detection, read personal stories about women and Alzheimer's, sign up for a monthly email celebrating women and their brains, and find out how to stay informed, stay in touch, raise your voice and even participate in promising new research.

Your brain is trying to tell you something. It is worth fighting for. Join the movement today at

[mybrain.alz.org](http://mybrain.alz.org)

save the date

## Webinar to Feature 2014 AAIC Highlights



Don't miss this upcoming 2014 Alois Society Webinar, featuring highlights from the Alzheimer's Association International Conference®.

Thousands of researchers from more than 60 countries are gathering this month to reveal the latest study results, theories and discoveries bringing the world closer to breakthroughs in dementia science.

Please mark your calendar with the following information:

**When:** July 22 at noon CST

**Topic:** The 2014 Alzheimer's Association International Conference

**Presenter:** Heather Snyder, Ph. D., Director, Medical and Scientific Relations

**Webex Conference:** [alz.org/AloisSocietyWebinar](http://alz.org/AloisSocietyWebinar)

**Audio:** 866.316.2054

**Passcode:** 755-7599-7802

We hope you will join with us for a chance to learn more.