

The Judy Fund News

A newsletter published exclusively for our friends and supporters

Care and Cure with the Alzheimer's Association

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An exciting year for Alzheimer's disease.

Crazy, yes? How can a disease that ranks as the sixth-leading cause of death in the United States, and the only disease among the top 10 without a means to prevent, cure or even slow its progression, possibly be exciting? What, exactly, is exciting about Alzheimer's? Well, 2012 is already a year of exciting developments in Alzheimer's science and policy.

Our nation has established a goal to prevent and effectively treat Alzheimer's disease by 2025.

The National Alzheimer's Project Act (NAPA) was signed into law by President Obama, committing our country to developing and implementing the first-ever national plan for Alzheimer's disease. And I am excited and hopeful not only for myself but also for the 78 million baby boomers in the U.S. today.

As a baby boomer, I know personally that we cannot wait to act any longer. As our population ages, so does our risk for developing Alzheimer's — in fact, age is the greatest risk factor for developing this horrible disease. An estimated 10 million baby boomers are expected to develop Alzheimer's in our lifetimes. Shockingly, the number of Americans that die each year from this disease has risen 66 percent since 2000.

Baby boomers are at tremendous risk of developing Alzheimer's disease. In just under 40 years, 16 million Americans will be living with Alzheimer's. Between now and then, America will spend more than \$20 trillion to care for people with Alzheimer's; Medicare spending on people with Alzheimer's will increase over 600 percent; and our families' out-of-pocket costs will grow more than 400 percent.

We can change these frightening statistics. The Judy Fund has been proudly supporting Alzheimer's Association initiatives to help alleviate the toll this disease takes on multiple generations — mothers and daughters, fathers and sons, grandparents. With your help, we have raised more than \$4.5 million to help fund the Association's care, support, advocacy and research efforts.

The fact is that left unchecked, Alzheimer's will become the disease of our generation. I am convinced we have to take action, get engaged and



Stephen Hume, Alzheimer's Association national board member and a boomer living with Alzheimer's

help achieve the real and attainable goal **to prevent and effectively treat Alzheimer's disease by 2025.**

You are an important part of advancing some of the latest and most exciting efforts to change the trajectory of Alzheimer's. None of us can do this alone. It will take all of us, working together, and now is the time. Every gift you give is working on the ground, helping make a difference and I hope you see that commitment inside this newsletter.

One boomer who is making a huge difference is my friend and fellow board member, Stephen Hume. Steve has been living with Alzheimer's for nearly five years. The disease has forced him into many powerful roles: advocate, educator and compassionate friend. He knows too well the toll of this disease on his own brain and on the hearts of others. **Steve, I dedicate this issue of The Judy Fund News to you. Your actions in the face of Alzheimer's have inspired me to take hold of the 2025 goal and charge forward.**

Changing the statistics of Alzheimer's is exciting, indeed.

Elizabeth

Elizabeth Gelfand Stearns
Chair

The Judy Fund

To read more about Stephen's personal story please go to page 9.

Please visit The Judy Fund's website at alz.org/judyfund for more information about how you can help in the fight against Alzheimer's.

National Alzheimer's Dinner

Alzheimer's Association honors legendary coach Pat Summitt at the National Alzheimer's Dinner

At a star-studded National Alzheimer's Dinner attended by celebrities, prominent politicians and Alzheimer's advocates in Washington, D.C., the Alzheimer's Association presented University of Tennessee Head Coach Emeritus Pat Summitt and her son, Tyler Summitt, with the Alzheimer's Association Sargent and Eunice Shriver Profiles in Dignity Award.

A leader in the Alzheimer's movement and former First Lady of California Maria Shriver, whose father Sargent Shriver passed away from Alzheimer's, presented the award, which recognizes an individual, organization or company whose actions have promoted greater understanding of Alzheimer's disease and its effects on diagnosed individuals, families and caregivers.

Summitt, the winningest coach in NCAA basketball history, publicly shared her diagnosis of younger-onset Alzheimer's disease last August at the age of 59. She and Tyler created The Pat Summitt Foundation Fund to provide grants to nonprofits like the Alzheimer's Association that raise awareness of the disease, support families and advance research.

"Coach, you've said that champions don't shy away and you have a championship team right here," Shriver said. "We've needed a coach for a really long time. And we will line up to be coached by you."

Summitt took to the stage with Tyler to receive the award. "I want thank the Alzheimer's Association for honoring Tyler and myself. This award is very, very special," Summitt said. "I have to admit when I first received a diagnosis last May, it threw me for a loop. I just didn't know what to think and what to do. Finally Tyler and I came to a decision to fight and to fight publicly."

"My mother teaches me every day that victories are a result of hard work, and that the team always comes before yourself," Tyler added. "We're so happy to be on this team."

In closing, Summitt rallied the crowd. "By working as a team, we can make a difference. We can make a difference in the lives of people who are living with the disease and the millions of people who are caring for them. Keep fighting, keep caring, and together we will win."

Hosted by Meredith Vieira, special correspondent for NBC News, whose brother is living with Alzheimer's, the National Alzheimer's Dinner brought together influential and respected political, business and entertainment leaders, as well as the broader Alzheimer's advocacy community, to inspire others to join the growing movement to end the disease.



Maria Shriver, Coach Pat Summitt and Elizabeth Gelfand Stearns

The Association presented a number of significant awards during the event, including the Alzheimer's Association Humanitarian Award, annually given to public officials who have made significant policy contributions to advance research and enhance care and support for people with Alzheimer's.

This year's award was presented to Sen. Debbie Stabenow (D-Mich.), for her continuing efforts to help produce a strong National Alzheimer's Plan and her work to introduce the Health Outcomes, Planning and Education (HOPE) for Alzheimer's Act in the Senate, and to Rep. Mike Burgess, M.D., (R-Texas), for his critical support of the passage of the National Alzheimer's Project Act and his position as an original co-sponsor of both the Alzheimer's Breakthrough Act and the HOPE for Alzheimer's Act in the House of Representatives.

Sen. Stabenow thanked the Alzheimer's Association for the award while calling attention to the greater fight to end this disease.

"I appreciate your recognition, but what it is more important to me is that in a few years we can say we made a huge difference in Alzheimer's research," she said. "That is the real reward for each and every one of us."

Similarly, Rep. Burgess acknowledged his award while keeping his focus on the larger picture.

"I appreciate being with you during this great evening. I see many of my colleagues in the audience and their efforts to pass the legislation mentioned this evening should not go unnoticed," said Burgess. "And I also want to recognize you, the activists of the Alzheimer's Association. It's hard to make a difference, but you've had some big wins recently with the National Alzheimer's Project Act."

Continuing the string of notable award recipients, Col. Karl E. Friedl, Ph.D., director, Telemedicine and Advanced Technology Research Center (TATRC) at the U.S. Army Medical Research and Materiel Command, received the Alzheimer's Association Ronald and Nancy Reagan Research Award for significant advancements in Alzheimer's research. Col. Friedl was recognized for his leadership in supporting innovative, outcome-oriented research programs, including the Peer-Reviewed Alzheimer's Research Program, which has led to a better understanding of traumatic brain injury and its association to Alzheimer's disease.

"Thanks to the Alzheimer's Association for recognizing what my little team tries to do — to get money into the hands of clinicians in new and different ways," he said. "This is the time for us to push the science forward. New breakthroughs are right around the corner."

The awards portion of the evening concluded with the meaningful Alzheimer's Association Advocate Award, presented annually to an outstanding Alzheimer's advocate who displays extraordinary leadership.

This year's recipient, Garrett Davis, an Alzheimer's Association Advocacy Ambassador from North Carolina, created a play titled the "Forget Me Not Project," a tribute to his grandmother who died of Alzheimer's and the family members who cared for her. The play explores one family's experience with Alzheimer's and aims to raise awareness of the disease and the need for increased support, services and federal funding.

Davis recalled his poverty while growing up and his reaction to his grandmother's diagnosis of Alzheimer's disease, which was avoidance.

"I wanted to write a play to bring closure to my personal life. For the last two years I have traveled around the county, putting on my play," said Davis. "Being poor, I always wanted to make money, but now I just want to make a difference."

Vieira closed the evening with a call to action, rallying advocates and attendees to continue the fight against Alzheimer's.

"Be inspired by everything you have experienced here," she said. "This is the time to show your strength in numbers."

Part the Cloud

Part the Cloud raises Alzheimer's awareness, funds



Mikey Hoag and the Steering Committee

Part the Cloud, a volunteer-led, star-studded evening of entertainment and inspiration, raised nearly \$2 million for Alzheimer's research in northern California. Hosted by Alzheimer's Association Zenith Society member Mikey Hoag on May 15, the evening featured performances by the legendary Tony Bennett, Joan Baez and Mickey Hart. It also included appearances by former NBA great Bill Walton, Alzheimer's Association advocate and actress Virginia Madsen, Alzheimer's Association Champion and ABC News "Nightline" anchor Terry Moran emceed the dinner. More than 300 of Silicon Valley's most influential gathered at the Rosewood Sand Hill hotel in Menlo Park, Calif. for a beautiful and exciting evening that successfully raised awareness for Alzheimer's disease and much needed funding for research.

"I am thrilled that Tony Bennett and all of our distinguished guests were able to join us for such an important event," said Hoag. "The outpouring of generous support was so unexpected and the evening was beyond my wildest dreams. My hope is that the monies raised for research efforts in northern California — in the capable hands of the Alzheimer's Association — will help move the needle for a world without Alzheimer's." — **Mikey Hoag, Part the Cloud Founder and Chair**

A Daughter's Story: *Susan Disney Lord*

Before my Mother was diagnosed with Alzheimer's Disease I only had a theoretical understanding of it being a terrible diagnosis. Until I started watching my mother's mind and spirit slowly disappear, I had no idea that a cancer diagnosis would have been better news.....

Back in February 2006, I went to visit my mother one day, and I noticed that she seemed to be repeating herself far more than she ever had before. It's something that kids like to tease their parents about, telling the same stories over and over. But this was different. My mother lived alone at that time, so I took her to a neurologist and was shocked as I watched the doctor ask her question after question which she could not answer correctly.

What year is it? "1998" What season is it? "Summer?" Who is President? "Nixon." How could she not know these answers? Count backwards from 5: "5, 4, 3, 6, 1." Draw the face of a clock. The numbers were all over the page, the arrows pointed in random directions.....

My Mom was vivacious, extremely smart, and funny. She and my Dad were married for 50 years and Patty Ann was probably the most loyal, devoted, adoring wife of all time. Don't get me wrong, she was also a pistol. Patty didn't back down from a fight, and she preferred we all did things her way, but she was usually right about things. Patty had seen her share of the highs and lows in life. She watched her four children grow up and start their own families and give her 17 grandchildren. She was caregiver to both of her parents through their long illnesses, and also took care of her mother-in-law who lived to be 95.

When Mom was diagnosed it became clear very quickly that she couldn't live alone, so I hired a wonderful caregiver who lived with my Mom for over 5 years, until Mom died. I consider this woman a saint. Dorina did what I couldn't do: the day in, day out, feeding, bathing, dressing, entertaining. It's endless, it's boring, it's frustrating, it's exhausting, and it's unrewarding. More than anything, I feel very very blessed that our family could afford this full-time care.

That first year after her diagnosis was a magical time to me. I knew we had a window of time to enjoy each other, I was acutely aware of that fact and tried to make the most of it before it was too late. My mother and I had never really had a very good relationship before then. But when she got sick she was so grateful to me for helping her, and I soaked it all up while I could.

Several years went by, and my mother declined. She stopped speaking almost completely, but Mom always loved to hear music, and would tap her feet and hands in time with the music. She could even sing all the lyrics to It's a Small World After All, even when she could no longer speak, and it made her happy.

One day we discovered that she had a large tumor growing in her mouth. It was her fourth occurrence of oral cancer. This time she couldn't tell us there was a lump in her mouth, and by the time we found it, it was far too advanced to treat without drastic surgery, and you can't operate on someone in



Patricia Ann Disney and Susan Disney Lord

the advanced stages of Alzheimer's when there's no real hope of recovery. The cancer forced the end to come to her, and to us. It was awful, but something needed to bring her suffering to an end. One day she just stopped walking, in the middle of the room, she just stopped. And two days later she took her last breath while all of her children loved her off to her next place.

When I was younger my Mom used to look at me and shake her finger and say "One day you'll take care of me. I earned it!" She was right as usual, she did earn it. And it was an honor for me to take care of her, to give back some of what she had given to me. And I am endlessly devoted to and appreciative of Dorina, who cared for my Mom with such tender loving care until the end.

Last week I was cleaning out closets in Mom's house, and I found her last purse hidden in a drawer. Inside were her usual lipsticks with no caps, Kleenex, a pocket organizer which I'm sure she never understood, and written on the inside flap of the purse were her name and address and phone number. Before I was able to organize her care, she was getting lost in her own neighborhood, forgetting where she had lived since she was six years old, forgetting her own name. I'll never forget it: Patricia Ann Disney, a great woman.

I have served on the Board of the Alzheimer's Association Southland Chapter for two years. I met Elizabeth through our mutual involvement in fundraising and advocacy for Alzheimer's Disease, and through the fact that her brothers coach my two sons in little league baseball. We share a passion for finding a cure for this disease. I admire the Gelfand Family's many years of commitment to finding a cure, and Elizabeth's commitment to her mother and grandmother's legacy through the Judy Fund.

Donor Profile: *The Belin Family*

Growing a legacy of philanthropy

Tom Belin and his four siblings grew up with a deep sense of the importance of giving back. Tom credits his parents, David and Connie Belin, with instilling these values in them early in life.

He fondly remembers a family meeting in which his parents announced they were joining a local country club in their hometown of Des Moines, Iowa.

"My siblings and I were so excited," Tom recalled. "Then my parents said, 'But this is something just for us, so we want to do something for someone else, too.'" So the elder Belins donated an equal amount of money to support a foster-child program overseas.

"That experience has remained with me throughout my life," Tom said.

Connie Belin, an educator who served on the Iowa Board of Regents, passed away from breast cancer. David Belin, a prominent attorney who wrote a book titled *Leaving Money Wisely*, later established the Iowa Foundation for Education, Environment and the Arts to advance charitable goals that were important to the family. As the Belin children grew older, they increasingly became involved in the work of the foundation, and they have managed the foundation since David Belin's passing in 1999.

Today, Laura Belin, the youngest of the Belin children, serves as president of the foundation in addition to other non-profit activities. After living in places as far-flung as London and Prague, she returned to Des Moines, where she and her husband are raising their two sons. Tom, a faculty member in biostatistics at the UCLA Fielding School of Public Health, has written or co-authored over 100 peer-reviewed articles in areas of health-science research. He explains that the foundation is unable to review grant solicitations on a large scale but that they look for opportunities to make a difference in areas that personally appeal to them.

The Judy Fund has become one such area of interest. After Tom relocated to California, he moved into the same neighborhood as Elizabeth Gelfand Stearns. Their children overlap in age, and their shared efforts through local PTA and Booster Club activities cemented a deep friendship.



Tom and his sister Laura

"I got to know Elizabeth through other philanthropic work she has done, and I have been so impressed over the years with the spirit of generosity that she and her husband Richard have brought to our local community," Tom said. "I did not have the privilege to know Judy Gelfand, but I greatly admire what the Gelfand family has done through The Judy Fund to advance research and treatment for Alzheimer's disease."

When a family friend who had been diagnosed with Alzheimer's disease passed away recently, Tom and his siblings looked to The Judy Fund again as a meaningful way to make a memorial gift.

"Pat Thompson, who had served on our local school board and in the Iowa Legislature, was a friend of our parents and the mother of my lifelong friend Paul Thompson," Tom said.

"She had a heart of gold, and when you see someone like that affected by this disease, you want to make an impact."

New online tools connect caregivers, people living with Alzheimer's

When facing Alzheimer's disease, it helps to connect with others who are going through similar experiences. It also helps to have easy access to reliable information and resources. The Alzheimer's Association has created a number of online tools to assist people with the disease and their caregivers.

ALZConnected links people with others facing Alzheimer's

ALZConnected™, powered by the Alzheimer's Association, is the first social networking community designed for people living with Alzheimer's and their caregivers.

Users can connect and communicate with others who are facing the same or similar challenges. They can also pose questions and offer solutions to dementia-related issues, create public and private groups organized around a dedicated topic and contribute to message boards.

Members are able to communicate and share as they please, including:

- Post a personal update and read what their "connections" have to share.
- Share questions and opinions with a diverse community.
- Get answers to questions or support others by offering solutions to their challenges.
- Rate solutions by indicating if that solution has been successful.
- Send private messages to "connections" within a secure system.
- Join public or private groups focused on a topic or shared experience.

Visit alzconnected.org today to join a community of support for those facing Alzheimer's.

Alzheimer's Navigator guides individuals and families through the disease

A diagnosis of Alzheimer's disease or related dementia raises many questions for people with the disease and their caregivers. And everyone's situation is different. The Alzheimer's Association created Alzheimer's Navigator™, an online assessment program to help people with dementia and their caregivers evaluate needs, execute and coordinate action steps, and be linked to Association chapter programs, local community services and referrals.

After answering a welcome survey, users receive recommendations for additional in-depth surveys tailored to specific needs. Survey responses help formulate a customized action plan featuring suggestions, tips and strategies and links to materials and resources.

Alzheimer's Navigator is designed to work with users as their needs change. Users can take other surveys when needed or even re-take previous surveys, making the personalized action plan a helpful guide through the progression of the disease. People can also create a care team to keep family members, friends, physicians and other interested individuals updated and involved in the care process.

Visit alzheimersnavigator.org for more information and to get started.

Community Resource Finder lets users find the help they need

For people with Alzheimer's and their caregivers, finding reliable resources close to home can make a difference in quality of life and planning for the future. The Alzheimer's Association's Community Resource Finder is a comprehensive database of legal experts, housing and care options and programs and services.

Community Resource Finder makes it easy to quickly search, find and access support — all in one place and with the benefit of consumer reviews and ratings.

Users can find resources in two easy steps:

- Enter the location of where you need services.
- Select the category of search results you want, then narrow down your choices.

Links to resources include:

- Residential care (adult family homes, residential facilities).
- Medical care (hospice, hospitals, pharmacies).
- Alzheimer's Association (education programs, support groups, events).
- Local services (adult day programs, home health care, transportation).

Visit [Community Resource Finder at communityresourcefinder.org](http://CommunityResourceFinder.org).

New Memory Assessment Center in Coachella Valley to increase service delivery

A partnership between Eisenhower Medical Center, USC Keck School of Medicine and the Alzheimer's Association, California Southland Chapter

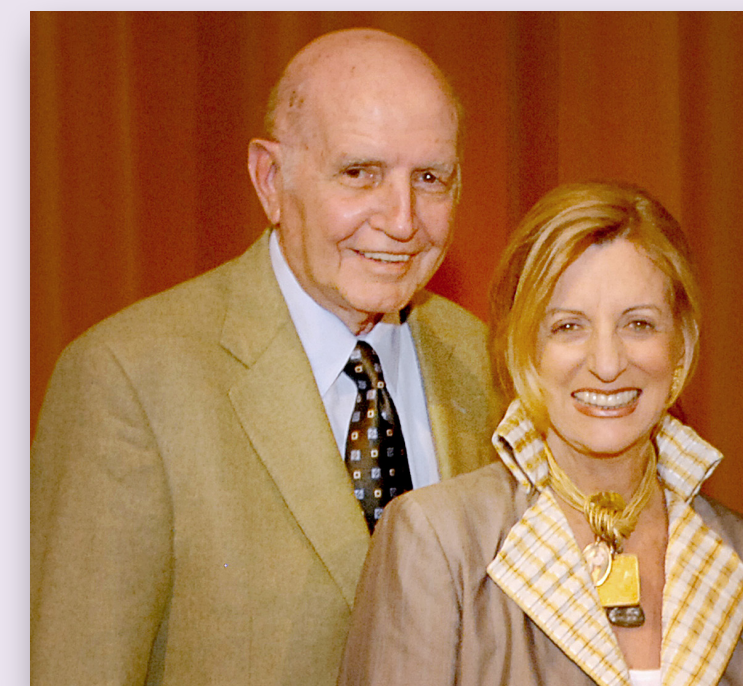
The Memory Assessment Center (MAC) at the Eisenhower Medical Center in Rancho Mirage, Calif., founded in 2007 thanks to the generosity of Ann and Bob Byfield, Helene Galen and The Judy Fund, has served hundreds of Coachella Valley residents concerned about memory loss. Recognizing a need to increase access to the MAC, a new model was established that will provide ongoing, weekly opportunities for memory assessments, as well as continued coordination with the Alzheimer's Association California Southland Chapter service delivery team.

The MAC is now located in the Uihlein (ē-line) Building on the campus of Eisenhower Medical Center (sharing space with Eisenhower's Primary Care 365 location) under the co-direction of Sheda Heidarian, M.D., and Collins Liu, M.D. Currently, clients who had previously scheduled appointments or needed follow ups are being contacted, and the MAC re-opened its doors to new referrals beginning in September.

Dr. Heidarian is board certified in internal and geriatric medicine, earning honors in various medical fields. She genuinely loves working with her patients and is a warm, empathic physician. Dr. Liu is assistant professor of clinical neurology and radiology at USC. He has a passion for improving the diagnosis and treatment of people with Alzheimer's using advanced neuroimaging techniques and is excited about his new role with the MAC. Roxanna Farinpour, Ph.D., who has been an important part of the assessment team since 2008, will continue as the MAC's neuropsychologist.

Everyone involved in this new partnership recognizes the importance of patients maintaining relationships with their current primary care physicians and specialists. The goal is to increase referrals, build stronger relationships with area physicians, and provide more enhanced educational opportunities about Alzheimer's and related dementias for physicians, their staff and the community. This new model will decrease waiting lists and increase the number of Coachella Valley residents who will be served.

If you have questions about the MAC or would like more information, please contact Stephen Harmon, regional director, Coachella Valley, Alzheimer's Association California Southland Chapter, at sharmon@alz.org or 760.328.3109.



Marshal Gelfand and Helene Galen

The Judy Fund plays a vital role in numerous *Advocacy Victories*

Due in part to the ongoing generosity of its dedicated members, The Judy Fund has a history of supporting the advocacy efforts of the Alzheimer's Association. This support has helped to advance the Alzheimer's movement and has contributed to the Association's major accomplishments.

Over the past several years, The Judy Fund has charitably sponsored a number of Association advocacy initiatives, including, but not limited to:

- The Alzheimer's Ambassador Program, designed to have one person from each of the nation's 535 congressional districts serve as a local point of contact for Alzheimer's advocacy with legislators. Ambassadors are responsible for scheduling regular meetings with their members of Congress and staff to build rapport and request action on the Association's legislative priorities.
- *Changing the Trajectory of Alzheimer's Disease: A National Imperative*, an Alzheimer's Association report that defined how a breakthrough in research would positively impact the trajectory of spending on care and support of people with Alzheimer's.
- Alzheimer's policy advertising in Capitol Hill publications such as *The Hill*, *Roll Call* and *Politico*, to raise awareness and concern with elected officials.
- The Washington, D.C., leg of the Breakthrough Ride, in which participants took a cross-country bicycle journey to Capitol Hill to deliver more than 100,000 signatures to Congress.

Most recently and importantly, The Judy Fund helped support the Association's greatest legislative victory — the passage and enactment of the National Alzheimer's Project Act (NAPA). Passed unanimously by Congress in 2010 and signed into law by President Obama on Jan. 4, 2011, NAPA's mandate was the creation of the National Alzheimer's Plan — the nation's first-ever strategic plan for Alzheimer's.

After the president signed NAPA, thousands of Alzheimer's advocates participated in more than 130 public input sessions, and nearly 250,000 people signed an online petition urging lawmakers to follow through on NAPA's promise. When the national plan was announced on May 15, Harry Johns, Alzheimer's Association president and CEO said, "This is a strong plan that promises important progress when implemented. For all Americans — not just the more than

5 million living with Alzheimer's and their 15 million caregivers today — this plan is an historic achievement."

In addition to the National Alzheimer's Plan, the federal government increased fiscal year 2012 Alzheimer's research funding at the National Institutes of Health by \$50 million and earmarked \$26 million to a targeted awareness campaign, immediate additional support for caregivers and a retraining program for health care professionals on Alzheimer's and dementia. At the 2012 Alzheimer's Association Advocacy Forum in Washington, Health and Human Services Secretary Kathleen Sebelius commended advocates on their devotion to the Alzheimer's cause and reiterated the Obama administration's commitment to the fight against the disease.

"You've changed the face of Alzheimer's," she said. "You've restored the dignity people with the disease thought they lost. You've made it possible for individuals and families to speak out and ask for help. In the process, you've made it impossible for political figures to ignore the disease."

"We still have a lot of work to do, but working together, we found the resources, the energy and the focus to bring Alzheimer's out of the shadows. The Obama administration wants to be a good partner, and we're in it for the long haul."

With Secretary Sebelius' appearance and a record attendance of more than 700 inspired advocates representing all 50 states, the 2012 Advocacy Forum was a rousing success. From the Rally to Remember to educational sessions to in-person visits with lawmakers on the event's final day, advocates took an active role in the Alzheimer's discussion by converging on the nation's capital with an already passionate sense of purpose — and by leaving with an inspirational recommitment to fighting the Alzheimer's battle on all fronts.

"The energy (at the Forum) to change things is just palpable," Johns told attendees. "It energizes me, and I can tell it energizes you. We need that energy to move things forward."

If history is any indication, The Judy Fund will continue to play an energetic role in supporting the Association in its role at the forefront of Alzheimer's advocacy.

National Alzheimer's Plan: *A Personal Perspective*

by *Dr. Stephen Hume*

It isn't every day that I am asked to sit in a room and listen to 24 highly educated and dedicated professionals plan my future. This opportunity presented itself when I attended the National Alzheimer's Project Act (NAPA) Advisory Council meeting in Washington, D.C. on Jan. 17, 2012.

Four and a half years ago, my partner Candy and I sat in a small office at our regional medical center waiting for the chief of neurology to give us a diagnosis.

I knew there was something wrong with my cognitive functioning and had undergone an extensive testing regimen in the proceeding weeks. I was very anxious. Candy had tried to reassure me, but had not been able to lessen my fear.

The doctor came in, sat down and said in a kind but matter of fact manner, we've ruled out everything we can fix — you have early-stage Alzheimer's disease.

At that moment, I shut my eyes and saw a room full of open doors each representing a future path for my life. Suddenly, they all slammed shut and I was in the dark. I could hear Candy's voice calling me back to the room and heard her ask the doctor about the course of the disease.

He told me, "Your world will shrink until it becomes the size of the chair you are sitting in." I was 60 years old and had just been given what to me was a death sentence — an end to all I valued — my intellect and the close connections I had with others.

At the time of my diagnosis, I was working as a behavioral healthcare executive and a practicing psychologist. It took several years for my symptoms to reach a level where I was forced to accept that I could no longer do the work I loved. I resigned my position eight weeks after my diagnosis.

It was also clear that Candy would have to work well beyond her planned retirement to pay for services that would allow me to remain at home in a safe and dignified way. I also know that she faces years of stressful caregiving as I continue to decline.

Through my work with the Alzheimer's Association, I have been able to raise concern and awareness of Alzheimer's across the country. I speak at caregiver and professional education conferences, legislative assemblies and have even spoken at the White House. Three years ago, I was elected to the Alzheimer's Association National Board of Directors.

As a behavioral health professional, I knew that advocacy was hard work and took time. I have to say, however, that I was surprised at how difficult it was to raise concerns about Alzheimer's disease despite the fact that it is the sixth-leading cause of death in the U.S.



Stephen Hume and his partner Candy Darcy

Fast forward to January 17 and I am at the NAPA Advisory Council meeting at the U.S. Department of Health and Human Services (HHS) building. The formation of the Council was mandated by the passage of the National Alzheimer's Project Act, which was signed into law by President Obama in January of 2011. NAPA called for the creation of a National Alzheimer's Plan to comprehensively address the Alzheimer's epidemic.

This was the Council's second meeting and it was apparent that the members were excited. HHS had just released an initial framework for the National Plan that would follow later in the year.

During the day and a half proceedings, I listened intently and for the first time in four years, felt hopeful. I truly felt that the Council and HHS were invested in producing an effective and courageous plan that would affect the course of this disease. A member spoke about the difficulty in funding services for patients and in increasing research dollars. Someone voiced that it had to do with the stigma, misconceptions and myths associated with the disease. Others agreed.

As the meeting ended, I thought about that remark and realized that despite the care that went into crafting the NAPA legislation and the excellent work of the Council, we didn't need to look beyond this room to understand the stigma, myths and misperceptions. I was attending a meeting where people were planning my future and the future of all those with Alzheimer's, yet there was no one with the disease at the table.

Now that the National Alzheimer's Plan has been released — and an ambitious target for the end of the disease has been set (the year 2025) — it is my hope that more room will be made at the table for people living with the disease to have a direct and ongoing voice in our own futures.

Because, if we are all successful together, millions of Americans will be freed from the personal and financial devastation of this terrible disease.

This essay was originally published on the Alzheimer's and Caregiving blog that can be found at mariashriver.com. It is being republished with permission.

Groundbreaking Research

revealed at AAIC2012

At the Alzheimer's Association International Conference 2012 (AAIC) in Vancouver, more than 4,300 members of the global Alzheimer's scientific community came together to discuss and share the latest discoveries and theories in the field.

AAIC is the largest forum for dementia researchers in the world. In Vancouver, attendees networked and exchanged ideas during approximately 2,500 scientific presentations covering the spectrum of Alzheimer's disease and dementia research, including causes, risk factors, detection and diagnosis, treatment and prevention.

"The good news is that we are making advances toward earlier detection of Alzheimer's, greater knowledge of dementia risk factors, and better treatments and prevention," said William Thies, Ph.D., Alzheimer's Association chief medical and scientific officer. "These advances are critical in order to create a future where Alzheimer's disease is no longer a death sentence but a manageable, treatable, curable or preventable disease."

Alzheimer's Therapies Update

IVIg stabilizes Alzheimer's in clinical trial

At AAIC 2012, the first report of long-term (three-year) stabilization of Alzheimer's disease symptoms with intravenous immunoglobulin (IVIg/Gammagard, Baxter) was presented. IVIg is being studied as an immunotherapy for Alzheimer's.

Participants in the original Phase 2 study received six months of treatment followed by a 12-month open-label extension with several doses being tested. Participants were then offered additional IVIg treatment at a single standardized dose for an additional 18 months. Study participants treated with the standardized dose for the full 36 months had the best outcome, with no decline on several standard measures of cognition, memory, daily functioning and mood at the three-year endpoint.

While the small number of participants may limit the reliability of the findings, the results are tantalizing. A Phase 3 trial is in progress and there will soon be more definitive data.

Upcoming prevention trials

Updates were given on three new Alzheimer's disease prevention trials that are beginning soon or are in the planning stages.



Two of the studies —by the Alzheimer's Prevention Initiative and the Dominantly Inherited Alzheimer's Network — will be conducted in families affected by younger-onset genetic Alzheimer's. The third study, proposed by the Alzheimer's Disease Cooperative Study, is known as the Anti-Amyloid Treatment of Asymptomatic Alzheimer's Disease (A4) trial. A4 scientists will study participants aged 70 and over who have normal memory and thinking abilities, with evidence of Alzheimer's changes in their brains shown on a PET scan using a special imaging dye.

Alzheimer's Early Warning Signs and Risk Factors

Late-life drinking, binge drinking and cognitive decline

Light to moderate alcohol consumption has generally been considered to have some health benefits. However, two studies suggested that moderate alcohol use later in life, heavier use earlier in life, transitioning to drinking later in life and "binge" drinking later in life increase risk of cognitive decline.

In one study, researchers followed more than 1,300 women aged 65 and older for 20 years. They found that:

- Women who reported drinking more in the past than at the beginning of the study were at 30 percent increased risk of developing cognitive impairment.
- Moderate drinkers at baseline or at midpoint had similar risk of cognitive impairment to non-drinkers; however, moderate drinkers in the late phase of the study were roughly 60 percent more likely to develop cognitive impairment.
- Women who changed from non-drinking to drinking over the course of the study had a 200 percent increased risk of cognitive impairment.

According to the researchers, doctors and other health care professionals should carefully assess their older patients for both how much they drink and any changes in patterns of alcohol use.

Clinical trials of exercise

Four studies indicated the ability of targeted exercise training to promote improved mental functioning and reduced risk for cognitive impairment and dementia in cognitively healthy older adults and those with mild cognitive impairment (MCI). The reports, from 6- and 12-month randomized controlled clinical trials, depict the beneficial effects of different types of exercise — resistance training, aerobic training and balance-stretching training — on a variety of cognitive abilities, brain structure and risk factors for cognitive decline such as depression and sleep quality.

These new studies begin to clarify exactly which types of physical activity are most effective, how much needs to be done and for how long. Where previous research showed positive associations between aerobic activity, particularly walking, and cognitive health, these new reports suggest that resistance training is emerging as valuable for older adults. It is generally accepted that regular physical activity is essential to healthy aging; it also may prove to be a strategy to delay or prevent the onset of cognitive impairment and dementia.

Gait changes

Gait disturbances — such as a slowing of walking pace or more variable strides — could indicate a decline in cognitive function. In general, scientists found that gait became slower and more variable as cognitive decline progressed.

- One study in Switzerland followed 1,153 older participants who had a range of cognitive abilities from healthy cognition to severe Alzheimer's. Results suggested that walking speed slowed as cognition worsened. Those with Alzheimer's in the study walked slower than those with MCI, who in turn walked slower than those who were cognitively healthy.
- A study from the Mayo Clinic Study of Aging explored the stride length, cadence and velocity of more than 1,341 participants through a computerized gait instrument at two or more visits 15 months apart. Participants with lower cadence, velocity and amplitude of the stride length experienced significantly larger declines in global cognition, memory and executive function.



Dr. Albert presenting at a focused topic session on the research priorities of the National Alzheimer's Plan

"For busy doctors with limited time with patients, monitoring deterioration in a patient's gait is ideal because it doesn't require any expensive technology or take a lot of time to assess," Thies said. "It may provide early detection of fall risk and the earliest stages of cognitive impairment in older adults."

Remembering Judy

My mother, Judy Gelfand, could not be defined. She was equally as interested in raising money to build hospitals and synagogues as she was in joining me at a Grateful Dead concert. I loved that about her. She could not be put in a box. She was limitless.

As the youngest child in our family, I had a special relationship with my mother. Growing up educationally challenged, let's just say my childhood was an adventure for everyone involved. But Mom never let it get us down. She believed in me and taught me about The Little Engine That Could — that anything in this life is possible you just have to dream it and make it happen.

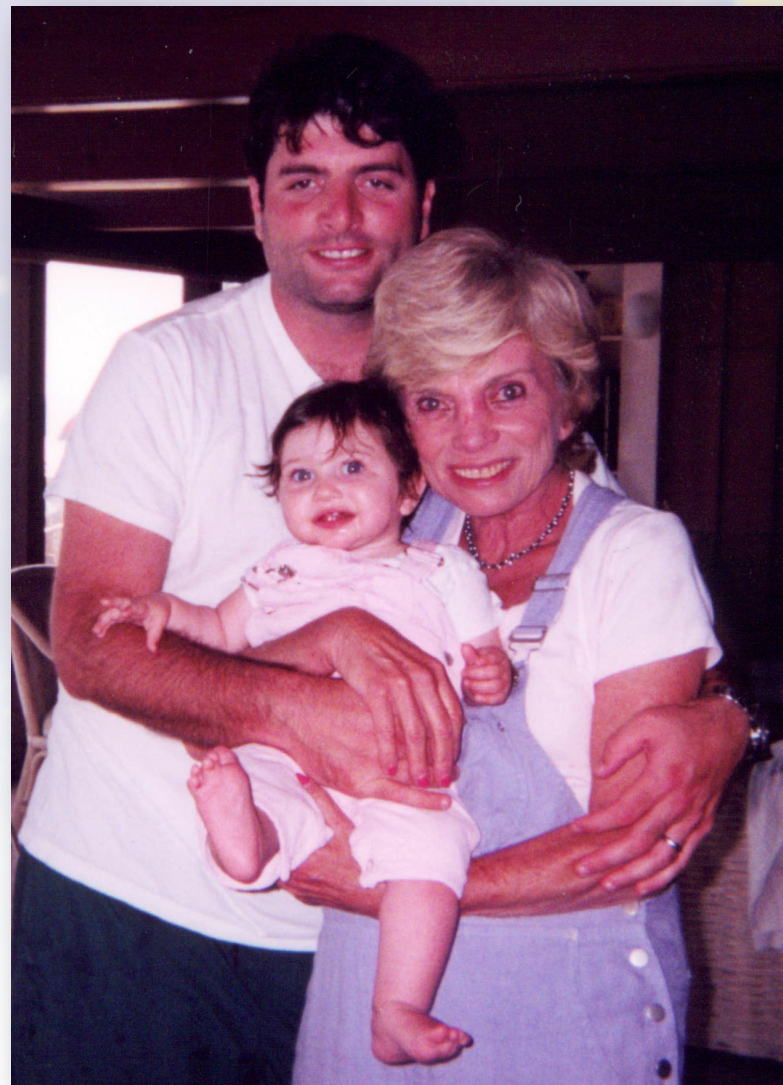
Mom was an eternal optimist, always seeing the glass as half full. She taught me about the bittersweet nature of life — that in every bitter moment, there is a silver lining. My optimistic nature, well known among family and friends, comes from her.

Mom had friends in all shapes and sizes, from all different backgrounds and paths of life. She was so very relatable, and she cared about each one of them. When Mom was diagnosed, I thought,

“Alzheimer’s, you messed with the wrong woman.”

I imagined that my mother, always committed to helping others, must have been dealt this wrong hand so she could make a difference. The Judy Fund, now eight years old, has raised over \$4.5 million to help others live with the disease that killed her. To survive and continue to fight this fight, The Judy Fund needs everyone’s ongoing support.

Throughout her battle with Alzheimer’s, my mother continued to do the things she loved. A classically trained pianist, she could sit down some days and play elaborate Chopin and Bach melodies from memory. On other days, she couldn’t even find the keys. She was rigorous about exercising and would walk every morning and every evening at sunset. I would often visit her in Palm Springs and meet a new caregiver, only to return months later to find the caregiver had dropped 20 pounds after walking every day with Mom.

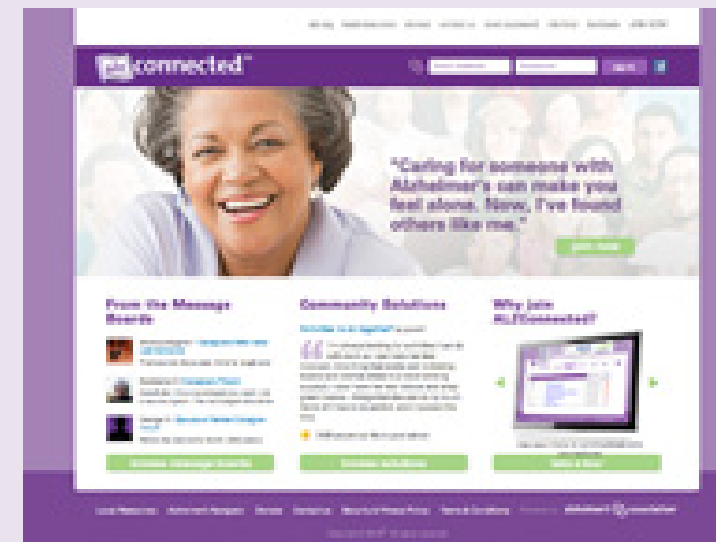


Dean Gelfand, with this mother Judy Gelfand and Dean’s daughter, Sophie Ella Gelfand, Summer 2000

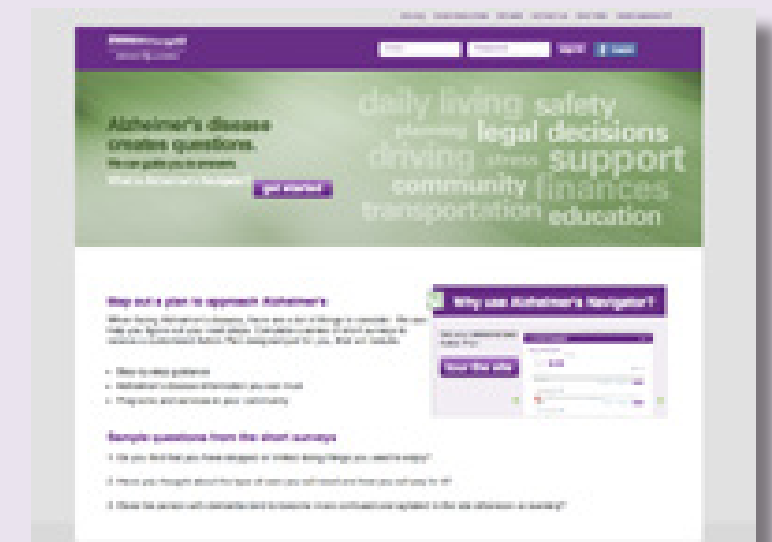
And through it all, she remained steadfast in her role as a mother. Caregivers would describe her behavior while I was visiting as different, more alert. Even in her later days with Alzheimer’s, she was still my mom.

These days I don’t think of Mom with Alzheimer’s. She didn’t let the disease define her, nor do I remember her that way. All I remember is my beautiful and loving mother, taking care of all of us, always present in our lives. In some ways, she is here now more than ever.

Get connected with new Alzheimer’s Association online tools



ALZConnected™ — a social networking community where people affected by Alzheimer’s can connect.



Alzheimer’s Navigator™ — an online tool for creating customized action plans of information, support and resources.



Community Resource Finder — an easy-to-search, comprehensive database of local resources.

Women & Alzheimer's: Dr. Marilyn Albert

Marilyn Albert, Ph.D., a leading Alzheimer's researcher and past Chair of the Alzheimer's Association Medical & Scientific Affairs Council, shares tips for keeping your brain fit through the years.

There may not be anything we can do to stop the passage of time. But just as you eat right and exercise to stay fit through the years, there are things you can do to help keep your brain healthy as you age. According to Marilyn Albert, Ph.D., Professor of Neurology at Johns Hopkins and co-author of the popular guide *Keep Your Brain Young*, lifestyle choices you make now could help maintain your memory later in life.

The four keys to maintaining brain health through the years are:

- Stay physically active
- Stay mentally active
- Stay socially engaged
- Control vascular risk factors

“We know that most diseases, including Alzheimer's, don't have a single cause; there are multiple causes,” Dr. Albert explained. “That's why these lifestyle choices are important. Each little thing you do might make some inroads in the prevention of disease, or might, in the end, add up to making a very big difference.”

And, at the least, Dr. Albert adds, “doing these things won't hurt us.”

Stay physically active

According to Dr. Albert, exercise is important to cognitive health because it maintains blood flow to the brain, and can help repair damaged brain cells and encourage the formation of new blood cells. “Research shows us that animals who are more physically active have an increase in trophic substances that help repair the brain and help it function better,” she explained. “The assumption is it's a similar phenomenon in humans.”



Marilyn Albert, Ph.D., Professor of Neurology and Director of Cognitive Neuroscience at Johns Hopkins University

If you're not a regular exerciser now, don't worry about starting out slowly. The important thing is to get out there and do something. “It doesn't have to be running 10 miles a day; it could be walking regularly. Any kind of aerobic activity seems to be beneficial,” Dr. Albert said.

Stay mentally active

All those people puzzling over their Sudoku books are on to something, as research shows that mentally stimulating activities strengthen brain cells and may help create new nerve cells. “When you're mentally active, you're making more connections between nerve cells in the brain, and then if some of those connections are changed or lost, you have more of a reserve to fall back on,” Dr. Albert said.

If you're still working, there's a good chance you're being mentally challenged by your work responsibilities. But don't despair if you're out of the work force and despise Sudoku. According to Dr. Albert, there's no research showing one particular activity is best for maintaining cognitive health. The key is finding a mentally challenging activity you enjoy, as it's more likely you'll stick with it. “Read a stimulating book, go to a lecture or learn a new hobby,” she recommends. “My mother took up Tai Chi at 99.”

Stay socially engaged

Scientists don't understand why or how being socially engaged makes a difference in cognitive health, but numerous studies show that it does. Research shows that emotional support and close personal relationships appear to have a protective effect against dementia. Dr. Albert points to one study that showed people who volunteered in the schools also saw beneficial effects.

Control vascular risk factors

“We know that smoking, high cholesterol, high blood pressure and being overweight all put you at risk for vascular disease,” Dr. Albert said. “But you don't just have trouble with your heart, you also have trouble with your brain.”

That's because your brain is nourished by one of your body's richest networks of blood vessels. Every heartbeat pumps about 20 to 25 percent of your blood to your head. Controlling vascular risk factors help ensure a good blood supply to your brain and may lower the risk of dementia and memory loss.

Take action

Of course, there are people who do all these things and still get Alzheimer's, Dr. Albert noted. Taking these brain-health steps may not prevent Alzheimer's, but it might lower the risk. And for many, particularly those of the baby boom generation, doing something is better than nothing, Dr. Albert said. “This generation is much more focused on prevention and taking action to prevent disease,” she said. “We want to be able to do something, we don't want to be passive, and these are good steps for anybody to take.”

Save the Date

Tuesday February 26, 2013

Los Angeles, CA



The Judy Fund and the Gelfand family invite you to meet a global and scientific leader, Maria C. Carrillo, Ph.D., Alzheimer's Association senior director, Medical and Scientific Relations.

Maria C. Carrillo, Ph.D., Alzheimer's Association senior director, Medical and Scientific Relations has a multitude of responsibilities at the world's leading voluntary health organization in Alzheimer's care, support and research. In addition to overseeing the Association's International Research Grant Program, through which the Association funds research, she supervises all communication of scientific findings within and outside of the organization. Dr. Carrillo also manages several initiatives, including the Alzheimer's Association Research Roundtable, a forum for pharmaceutical companies to discuss trends in Alzheimer's research and therapeutic targets; the World Wide Alzheimer's Disease Neuroimaging Initiative (WW-ADNI), a multi-country research effort aimed at finding biomarkers for early detection of the disease; and the Working Group on Technology (WGT), which promotes the use of current technologies to help individuals living with Alzheimer's retain their independence as long as possible.

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“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.” Margaret Mead

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Care and Cure with the Alzheimer's Association

september '12

World Alzheimer's Month

21 Alzheimer's Action Day

october '12

**22 Zenith Society
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23 Zenith Society Annual Meeting
Waldorf-Astoria
New York, NY

**25 New York City
Rita Hayworth Gala**
Waldorf-Astoria
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november '12

**4 Los Angeles Walk to
End Alzheimer's™**

**13 Southland chapter:
A Reason to Hope breakfast**
Palm Springs, CA

march '13

20 A Night at Sardi's
The Beverly Hilton
Beverly Hills, CA

april '13

22-24 Advocacy Forum
Washington, D.C.

may '13

11 Chicago Rita Hayworth Gala
The Hilton Chicago
Chicago, IL

july '13

13-18 AAIC®
Boston, Massachusetts

For more information about any of the above events, visit alz.org.



Ella Stearns and Sophie Gelfand

The Judy Fund Team Co-Captains, Walk to End Alzheimer's, 2012, Century City, California

Join Ella and Sophie and support The Judy Fund team at the Walk To End Alzheimer's® on Nov. 4 in Los Angeles. In honor of their b'not mitzvah in November, Sophie and Ella will lead our team and honor their family and millions of families around the world who suffer from Alzheimer's disease.

Join The Judy Fund team at act.alz.org/goto/thejudyfund and walk with us or donate. Thank you for joining our family mitzvah.

The Alzheimer's Association is deeply grateful to the families, friends, business colleagues and corporations who have so generously supported the founding and growth of **The Judy Fund**.

Marshall M. Gelfand and his family established **The Judy Fund** in 2003 in loving memory of his wife, Judy Gelfand. Since its inception, this family fund has raised more than \$4.5 million in support of the Alzheimer's Association to help prevent this disease from striking future generations.

Your support has enabled **The Judy Fund** to finance public policy efforts and vital research grants, including the Association's funding for Pioneer and Zenith Fellow Awards. Thank you for joining the Gelfand family in helping to advance the mission of the Alzheimer's Association.