Dear Friends and Family,

This summer offered me the opportunity to travel in France, where I learned many important things, among them: Sancerre as a daily ritual is a perfect compliment to a Paris afternoon; Jim Morrison has many famous neighbors resting alongside him at Père Lachaise and the literal translation for the word “memory” in French is *souvenir*.

What a delightful way to think about memories – as souvenirs of one’s existence, little treasures collected and preserved and appreciated over a lifetime. Some of these treasures are shared, some are kept private, but all have a home in the annals of the brain, categorized and stored, ready to spring into action when called upon. Hundreds of billions, (I actually read it was the equivalent of one million gigabytes) of tiny souvenirs of one’s life, built upon over a lifetime, additive, intact and stored in each human brain.

Alzheimer’s destroys those souvenirs and erases lifetimes. It is a thief of treasured possessions, robbing victims and families of generational knowledge. It is the destruction of a prized collection. It is the end.

Alzheimer’s has affected our family for four generations. My children’s great-grandmother Gertrude Glazer died of Alzheimer’s disease. Her daughter, my mother, Judy Jaffe died the same way. My brothers and I are the generation of change; our children will likely be the generation of survivorship. Surviving Alzheimer’s, a scientific concept that is likely to be a reality in the next couple of decades. I plan to be around to usher that science in.

We actively refer to the generations of The Judy Fund. The First Generation of the Fund is Judy and Marshall, their peers, and friends and family. JF2G refers to the Second Generation: Todd and Doreen, Dean and Marcie, Richard and I. We regularly reach out to engage friends and family of our generation in the cause. One example is our new “Judy Fund Salon Series,” which speaks to boomer women about the important connection between their brain and heart health (see story on page 11).

JF3G is the future: the eight grandchildren of Judy – the Third Generation of the Fund. We use many tactics to engage this younger generation in the work of The Judy Fund. From the work of the Sigma Alpha Mu fraternity on college campuses across the country, to Ella and Sophie, who at just 13 years old, are already co-captains of The Judy Fund Team for the Los Angeles Walk to End Alzheimer’s® – JF3G is making a significant mark on the future of this disease. Throughout this newsletter, you can read stories and reports on the generations of The Judy Fund, and how we bring so many people together to help us put an end to this disease.

Since The Judy Fund’s inception in 2003, we have raised nearly $5 million to support the research and public policy efforts of the Alzheimer’s Association. This continues to make us the fastest growing family fund in the history of the Association. We continue to grow and serve, for ourselves and for future generations. We want to keep the souvenirs of a person’s lifetime intact, and ensure they are there to be shared.

Help us grow, keep in touch, support our work.

Elizabeth

Elizabeth Gelfand Stearns
Chair
The Judy Fund

Judy on the Champs-Elysees, Paris, circa 1971

Elizabeth and Richard in Paris, circa 2013
Research: AAIC13
World’s largest dementia conference reveals promising new paths

AAIC 2013 research highlights include:

**Most kinds of cancer associated with decreased risk of Alzheimer’s**

Researchers announced a study of the health records of 3.5 million United States veterans indicating that most types of cancer are associated with a significantly decreased risk of Alzheimer’s disease. Results suggested that chemotherapy treatment for almost all of those cancers conferred an additional decrease in Alzheimer’s risk. The researchers found no association between cancer history and reduced risk of any other typical age-related health outcome; in fact, most cancer survivors were found to be at increased risk for non-Alzheimer’s dementia. The scientists concluded that the findings indicate that the protective relationship between most cancers and Alzheimer’s disease is not explained simply by increased mortality among cancer patients. More research is needed to determine the cause(s) of the reduced risk and identify potential new therapeutic avenues for Alzheimer’s.

**Older age at retirement signals a reduced risk of dementia**

An analysis of health and insurance records of more than 429,000 self-employed workers in France found that retirement at an older age is associated with a reduced risk of dementia, with a lower risk for each added year of working longer. Researchers suggested that professional activity may contribute to higher levels of intellectual stimulation and mental engagement, which may protect against dementia. More research is needed in this area.

**Commercial tests for Alzheimer’s do not measure up**

A panel of Canadian experts—including geriatricians, human-computer interaction specialists, neuropsychologists and neuroethicists—reviewed 16 freely accessible online tests for Alzheimer’s disease, and found that the tests scored poorly on scales of overall scientific validity, reliability and commercial conflicts of interests, failure to meet the stated scope of the test and failure to word the test outcomes in an appropriate and ethical manner.

**Self-reported changes in memory may be earliest clinical markers of Alzheimer’s**

Four studies supported increasing evidence that subjective cognitive decline (SCD)—the self-reported perception of memory or cognition problems—is a potentially valid early clinical marker of brain and cognitive changes that may indicate Alzheimer’s disease. In one study, cognitively normal older people showed a significant relationship between self-reported cognitive concerns and evidence of buildup of beta-amyloid protein, the main component of Alzheimer’s brain “plaques,” as revealed by PET scans.

In another study, older adults underwent annual cognitive assessments for an average of 10 years. Subjects who reported a change in memory since their last assessment were almost twice as likely to be diagnosed with mild cognitive impairment or dementia during follow-up than those who did not report such a change.

For more information on the dementia science shared for the first time at AAIC 2013, visit alz.org/AAIC.

Harry Johns, president and CEO, Alzheimer’s Association, welcomes attendees to AAIC 2013.


AAIC attendees listen during a scientific presentation.
Advocacy: Sammy and Judy
Sigma Alpha Mu Fraternity increases fundraising, seeks deeper involvement in Alzheimer’s Disease

Chase Huber, philanthropy chair of the Sigma Alpha Mu (ΣAM) Fraternity chapter at Kentucky Wesleyan University, was beaming with pride. His chapter had just been presented with an award from The Judy Fund at the 2013 ΣAM convention for “Most Donations Raised To-A-Sammy,” meaning that they raised the most money per man — per Sammy, as the brothers are known — of any ΣAM chapter in the 2012-2013 academic year. The 11 members of the Beta Omega chapter averaged over $110 in donations.

“My grandfather died from dementia,” Chase said. “It meant a lot to earn this award for all the hard work we did to collect the money for The Judy Fund and to share information so that people could become aware of the hardships of those with Alzheimer’s and those who care for them. All in all, I’m so incredibly proud of my chapter and of Sigma Alpha Mu for supporting an amazing cause.”

Huber’s enthusiasm and dedication to The Judy Fund are shared by many members of the active ΣAM brotherhood and its national leadership. They have been collaborating more closely in recent years with The Judy Fund to increase fundraising by its 50 chapters nationwide and to make the experience more meaningful for participating Sammies and other students.

Already, this effort is seeing results: In the 2012-2013 academic year, ΣAM chapters raised $52,848, a nearly 80 percent increase over 2011-2012. The chapter participation rate increased as well, from 20 chapters to 28.

“The recent growth in fundraising results that our chapters have achieved is a direct result of the support that they receive from members of the Alzheimer’s Association staff, as well as the commitment of our international organization to support this critically important effort,” stated Leland D. Manders, the fraternity’s executive director.

A family affair
Sammies have been raising money for The Judy Fund since 2005, when Sigma Alpha Mu made The Judy Fund its national charity of choice. Marshall Gelfand, an alumnus of ΣAM, was instrumental in forging this relationship.

“Few things in my life have meant more to me than Sigma Alpha Mu,” Gelfand said. “I’m so proud, and I know Judy would be proud, that her philanthropic spirit has inspired the entire brotherhood to rally behind this important cause.”

Gelfand is equally proud to see that the younger generation of his family are actively involved in both ΣAM and The Judy Fund and the advancement of this partnership. His oldest grandson, Brian Gelfand, pledged ΣAM at the University of Pennsylvania and was active in the chapter’s work to support The Judy Fund before his graduation in 2009. Grandson Greg Stearns is an active Sammy at the University of Michigan and is also involved in his chapter’s work for The Judy Fund.

Judy Fund Chair Elizabeth Gelfand Stearns partners with her father, Marshall, to run The Judy Fund, and she is leading the effort to deepen and broaden its relationship with ΣAM.

“I love working with Sammy to support its efforts in doing good things that make a difference,” Elizabeth said.

“The work we do together is a fine example of how fraternities and sororities can have fun and do meaningful work. Alzheimer’s is a disease of all generations, and it is great to see the enthusiastic participation of Sammies across the country.”

Hearing fun and doing good
The Eta chapter of Syracuse University, Marshall Gelfand’s alma mater, raised the most donations for The Judy Fund in 2012-2013, an impressive $9,674. Christopher Connolly, Eta president, attributes his chapter’s success to a number of factors.

“The keys to our success were staying enthusiastic and keeping our events open to everyone,” Connolly said. “If somebody wants to help our cause, then he or she should have full rights to join in no matter his or her organization, whether it be Greek life, sports, clubs, etc. Generous support from our alumni board is also crucial. We could not do these events without it.” He added, “Our traditions make raising money a lot more fun than people expect.”

These traditions include numerous multi-organization athletic competitions. The chapter’s newest competition features sororities vying against one another for the chance to have one of their members named Sammy Sweetheart. The events include football, dancing and a scavenger hunt. The chosen undergraduate from the winning sorority is featured as sweetheart on the chapter’s photo composite, and the sorority also receives a cash donation toward its own fundraising.

For raising the most donations for The Judy Fund, the Eta chapter received a $250 cash prize. In addition, Connolly and the chapter’s philanthropy chair won an all-expenses-paid trip to the 2014 Alzheimer’s Association Advocacy Forum in Washington, D.C. They will receive insider access to the Association’s annual gathering of Alzheimer’s advocates, from across the nation and lend their voices to the chorus on Capitol Hill advocating for those facing Alzheimer’s.

The Forum trip and the cash prize have been made possible by support from The Judy Fund, the Alzheimer’s Association and ΣAM.

The Judy Fund also provided cash prizes to the Beta Omega chapter for “Most Donations Raised To-A-Sammy” and to the Gamma Phi chapter at Arizona State University, which was the chapter most improved in fundraising. The chapter increased its fundraising in 2012-2013 by 90 percent over the previous year to $1,000. The cash prizes also will continue annually.

Giving back
Before the end of the banquet lunch where the awards and prizes were presented, the top three fundraising Sammy chapters approached Dan Parisi, a representative of the Alzheimer’s Association and The Judy Fund, to indicate that they were donating back their cash prizes. It was a remarkable gesture that speaks to the high integrity of the ΣAM brotherhood.

Julian Beuzieron, vice prior, Gamma Phi chapter, who was present to receive the award and prize, was asked what motivated him and his brothers to do this.

“Charity is not done for a reward,” he said. “While we were incredibly honored to be recognized for our fundraising efforts, it felt wrong to be taking back money from an organization that we just gave money to. We are glad that the money we donated, as well as the money we gave back, is making a difference and helping save lives.”
Thanks to the generous sponsorship support from The Judy Fund, the Alzheimer’s Association Ambassador Program is flourishing, with 435 advocates raising their voices across the country as part of a targeted effort to create policy change. Since the program began in 2010, it has expanded exponentially, reflecting the overall growth of the grassroots movement to end Alzheimer’s disease.

“The idea behind the program is to leverage our strong advocate base by asking them to build relationships with congressional district staff,” said John Funderburk, Alzheimer’s Association director of advocacy. “There’s a lot of noise on Capitol Hill, and we want to pierce through that noise.”

As an extension of the Association’s advocacy program, Ambassadors must apply for the position through their local chapter. They participate in monthly calls to receive policy updates and guidance on legislative issues and to learn about engagement opportunities.

Each Ambassador is asked to meet face-to-face with their assigned member of Congress five times a year — four times in their home districts and once in Washington, D.C., as part of the annual Alzheimer’s Association Advocacy Forum. They are also encouraged to share their personal experiences with Alzheimer’s in the media, at town hall meetings and by submitting letters and other written pieces to local and national publications.

Ambassadors have become essential to the overall success of the Association’s policy efforts, acting as an extension of the organization across the country. They are people living with Alzheimer’s, caregivers, family members and even researchers — individuals who share the common goal of putting a face to the disease for their elected representatives.

The Association’s Ambassador Program is unique compared to similar programs at other disease-related nonprofits. “We don’t start with a campaign donor file when selecting an Ambassador — in other words, we don’t look to see if an Ambassador has been politically involved with the representative in question,” said Funderburk.

The Association’s Ambassador Program is flourishing, with 435 advocates raising their voices across the country as part of a targeted effort to create policy change. Since the program began in 2010, it has expanded exponentially, reflecting the overall growth of the grassroots movement to end Alzheimer’s disease.

“Young Ambassador Leads the Fight

Steve Rabish, a 28-year-old Ambassador from Phoenix, doesn’t see Alzheimer’s disease as an old person’s issue.”

“It’s a young person’s issue,” Rabish said. “The time to take action is now, before the disease strikes and wipes your plans for the future.”

Sadly, Rabish was introduced to Alzheimer’s at an early age, as he watched his grandfather, a World War II veteran, deteriorate from the disease. Rabish wishes he had the opportunity to get to know his grandfather, who many family members tell him he resembles.

“*He had no idea who I was, “ Rabish said. “My parents had to tell me, ‘He does love you.’ For my grandfather, Alzheimer’s was a living death.*”

Now, in his role as an Alzheimer’s Association Ambassador and his career as a financial advisor, Rabish hopes he can help other families facing this devastating disease.

“People work so hard, and Alzheimer’s just destroys their financial resources,” he said. “And this not just about the money, it’s about the emotional impact, too.” At 25, Rabish walked into the Alzheimer’s Association Desert Southwest Chapter and asked what he could do to help. He immediately joined the Association’s advocacy program, and when the Ambassador program started in 2011, he was one of the first to sign on. In this role, he communicates the Association’s policy messages to Rep. Kyrsten Sinema (D-Ariz.).

“As an Ambassador, I represent the Association’s policy interests,” said Rabish. “And I’ve worked hard to develop relationships at the local level so I can have an effect.”

With the support of The Judy Fund, the Ambassador program is moving critical Alzheimer’s legislation forward across the country.

- Program has grown to include more than 430 Ambassadors.
- Along with their fellow advocates, Ambassadors made nearly 2,400 visits to elected officials in Fiscal Year 2012.
- These visits have reached every member of Congress.
- To date, Ambassadors have helped garner 155 co-sponsors for the Health Outcomes, Planning and Education (HOPE) for Alzheimer’s Act.

Rabish has also worked with fellow advocate Suzette Armijo to establish Young Advocates for the Alzheimer’s Association (YAAA!), a group of young professionals in the Phoenix area who strive to further awareness of dementia-related issues.

“Our elected officials are the gateway to change for Alzheimer’s disease,” Rabish said. “The private sector cannot solve this problem alone. Funding has to come through Congress.”
Research: Women & Alzheimer’s

Reisa Sperling, M.D., director of the Center for Alzheimer Research and Treatment at Brigham and Women’s Hospital in Boston, is leading the highly anticipated Anti-Amyloid Treatment in Asymptomatic Alzheimer’s Disease (A4) trial. This is the first time investigators will test an amyloid-clearing drug in older individuals thought to be in the presymptomatic stage of Alzheimer’s disease. A4 is a three-year study slated to begin at the end of 2013.

Dr. Reisa Sperling sat down with The Judy Fund News to discuss A4 and how she hopes it will help lead to a better understanding of the cause(s) of Alzheimer’s disease and possible preventative treatments.

Q: Why do you focus your work on prevention rather than treatment?
A: As a treating neurologist, I see patients in the clinic. It helps me keep me grounded in the realities of dementia and the fact that we must find a way to stop this disease from affecting millions of more people. I think we must continue to work toward developing treatments for people who are already living with Alzheimer’s disease at the dementia stage. But I truly believe, after doing clinical trials for 10 years, that we’ll have more success in treating people in earlier stages of the disease, when their brains still have nerve cells that we can rescue. And eventually we’ll have fewer and fewer people to treat for Alzheimer’s disease, as we’ll have effective preventative methods in place.

Q: Can you describe your upcoming A4 trial?
A: I am very excited to begin our A4 trial. We will select 1,000 participants ages 65 to 85 who are clinically normal but have evidence that their brains have abnormal accumulation of beta-amyloid protein, which is believed to contribute to causing Alzheimer’s disease. We will test an anti-amyloid treatment (EI Lilly’s experimental solanezumab) in asymptomatic Alzheimer’s disease.

There are three parts to the A4 study. First, one group identified as having abnormal buildup of amyloid will receive the selected treatment. Second, another group found with amyloid buildup will receive a placebo, an inactive, inanimate form of the selected treatment. Third, we will include an observational natural history group of people who do not have amyloid buildup, and we will follow the changes in them. We will include individuals who are worried about their memory but are still performing in the normal range. Sometimes people can see subtle memory changes in themselves before we can identify them using standard tests. We’ll explore the specific complaints that may signal increased risk for developing Alzheimer’s disease dementia.

Q: What is beta-amyloid and what role does it play in cognitive decline?
A: Beta-amyloid is a protein we all produce normally in the brain, although its normal function is not yet well understood. When there is abnormal buildup, beta-amyloid forms plaques and other accumulated forms. This accumulation is thought to be toxic to nerve cells. It disrupts the ability for one cell to talk to another, which is thought to affect memory. The role of this protein in Alzheimer’s disease is still unknown, but the A4 study will directly test this role by using an anti-amyloid therapy, solanezumab.

Q: What is tau and how does it differ from beta-amyloid?
A: Tau is another protein that is produced in nerve cells. When it accumulates abnormally, it forms clumps, known as tangles, inside the nerve cells and is also thought to be toxic to cells. Abnormally accumulated beta-amyloid creates clumps, known as plaques, outside of the nerve cells.

Q: What are you hoping to learn through these trials?
A: We’re hoping to learn whether decreasing beta-amyloid in the brain will slow the earliest cognitive decline. It’s the same idea as lowering cholesterol to reduce heart attacks. We’re trying to find out if lowering amyloid early enough in the course of Alzheimer’s disease will ultimately prevent Alzheimer’s-related dementia. We don’t know if amyloid is really the cause of Alzheimer’s, but for our study, it doesn’t have to be “the” cause; it only has to be a critical factor in the disease in order to make an impact. Much like high cholesterol is only one reason a person may have a heart attack.

While our main hypothesis is to prove that decreasing amyloid buildup in the brain will slow the rate of cognitive decline, we’re also running a parallel study to investigate a group of people who do not have an elevated level of amyloid. We want to find out why some people develop tau in the absence of amyloid and see whether they differ in the rate of cognitive decline over the three-year study.

We will also explore functional networks inside the brain. We’ll use MRI to not just look at the size of the brain, but also to examine how the brain functions and how well the circuits are maintained. For example, the hippocampus is important for memory. And while there is not a lot of amyloid present early in the disease process, there is a lot of tau. Our goal is to better understand the brain network and the relationship between the two proteins in altering brain function.

We would also like to better understand what is normal aging and what are the first signs of Alzheimer’s disease. I envision that we’ll one day be able to develop an algorithm — a simple series of tests to help determine if a person is at increased risk (genetic, age and concerns about memory), which might ultimately lead to selecting individuals for a positron emission tomography (PET) scan for amyloid or possibly tau buildup in the brain. Our goal is to figure out a strategy for finding those at highest risk and to be able to provide a preventative treatment before any symptoms are present. I’m very hopeful that we will get there.

Q: What is your perspective on how Alzheimer’s disease impacts women?
A: Alzheimer’s affects women at a disproportionate rate. At any given age, women are nearly two times as likely to develop the disease. And even if a woman is able to evade dementia clinically, she is very likely to serve as a caregiver for someone with the disease at some point in her lifetime. From a research standpoint, we need to find out why women are at a higher risk. And from an activism standpoint, we need women to stand up and fight. Through causes like breast cancer and childhood violence, we have seen what women can do with political might. I hope women will continue to step up and take on Alzheimer’s disease as a critical issue for all women.

Q: Why is it important to participate in clinical trials?
A: “I am convinced that we have potential disease modifying treatments for Alzheimer’s in the test tubes right now. Clinical trials are the only way we will find which treatments will effectively treat and ultimately prevent and cure the disease.”

Unfortunately, lack of enrollment in clinical trials is the bottleneck for Alzheimer’s clinical research. As we shift our focus to earlier and earlier stages, we need to screen more individuals in order to find the right subjects. People need to volunteer, not just for themselves, but for their children and grandchildren. We need everyone’s help in order to make Alzheimer’s disease a preventable illness.

Q: What is your perspective on how Alzheimer’s disease prevention can impact women?
A: Alzheimer’s prevention can impact women by providing opportunities to contribute to the scientific advancement of the disease and by giving women a voice in this area. Women’s engagement in clinical trials has the potential to make a significant impact on the disease, as Alzheimer’s affects women at a disproportionate rate. Women’s participation in research can lead to the development of more effective treatments and preventative methods.”

The Collaboration for Alzheimer’s Prevention (CAP) was established between our trial and two other prevention initiatives — the Dominantly Inherited Alzheimer’s Network (DIAN) and the Alzheimer’s Prevention Initiative (API). CAP was created with support from the Alzheimer’s Association and Fidelity Biosciences so that we can collect biomarkers and imaging data in a similar manner across these initiatives in order to evaluate whether the drugs have similar effectiveness in possibly delaying or stopping the onset of cognitive decline or related disease processes. We will acquire the samples and imaging data in a standardized way, allowing us to more accurately compare the findings of the trials.
Patty and Arthur Newman

Donor Profile:

Leading “the good fight” through philanthropy

Patty, a former college instructor and fashion industry executive, and her husband Arthur Newman, former film producer and brother to Academy Award-winning actor, Paul Newman, met Judy and Marshall Gelfand in Palm Springs in the early 1980s. The couples shared an interest in community service and a commitment to making the world a better place. Unfortunately, Judy’s fate didn’t cooperate.

“Effervescent”—it’s how Patty Newman describes the late Judy Gelfand. Sadly, the irony of that description is not lost on Patty as she recalls the way Judy’s vivaciousness and ultimately, her life were stolen by Alzheimer’s disease.

“Judy was a very ‘can-do’ type of gal,” Patty said. “Alzheimer’s disease robbed her of that ability. And in the end, took a great leader from society.”

Patty and Judy were both active with the Palm Springs Art Museum, where Patty continues to play a role today. Although she has been involved with philanthropy and nonprofit work since college, Patty was further motivated by Judy’s activism. “Judy was a true inspiration for developing a relationship with a cause and sticking to it,” she said.

Patty and Arthur Newman

Photo courtesy of the McCallum Theatre

After Judy’s death, Marshall approached Patty and Arthur to support The Judy Fund. Knowing Judy and others affected by Alzheimer’s, they did not hesitate to say yes. “I can’t imagine that there is anyone affected by this disease who isn’t immediately on board with joining the fight,” Patty said.

Through The Judy Fund, the Gelfand family has put the Alzheimer’s cause at the forefront in southern California. Patty said. “Alzheimer’s disease robbed people of their ability to cope with the disease, the cost of caregiving and the associated stress. It’s devastating.”

As grateful as Patty and Arthur are for the Alzheimer’s Association and its supporters, including The Judy Fund, they know more progress is needed.

“There has to be a greater power here. The government needs to take action. We’ve made some major headway, but we need to keep pushing. This country needs to focus on Alzheimer’s like it does cancer and AIDS,” she said.

The Judy Fund helps to address the need for additional government support of the fight against Alzheimer’s by contributing to Alzheimer’s Association advocacy efforts.

These initiatives ensure that necessary conversations about the disease continue to take place on Capitol Hill. In addition to raising funds and awareness for Alzheimer’s, Patty is hopeful that the Gelfand family, and its multi-generational interest across siblings, nieces, nephews and new spouses, will help show a younger generation the importance of philanthropy and encourage them to follow in the footsteps of people like Judy, Marshall, Arthur and herself.

“The Judy Fund is so very needed,” Arthur said. “I don’t think there’s a person today who hasn’t been touched in some way by Alzheimer’s. Everyone should support this cause to the extent their time and resources allow.”

By contributing to The Judy Fund, Patty and Arthur are able to help fight the disease that is taking an enormous financial and emotional toll on society — the same society they have worked so hard over the years to improve.

“We have got to get a handle on this disease. As a country, we’re aging. But we’re not aging as well as we should be,” said Patty. “There are more than five million people living with Alzheimer’s. That’s five million families who have to cope with the disease, the cost of caregiving and the associated stress. It’s devastating.”

Through The Judy Fund, the Gelfand family has put the Alzheimer’s cause at the forefront in southern California. Patty and Arthur, along with Newman’s Own Foundation, have been pleased to contribute to The Judy Fund and its unwavering support of the Alzheimer’s Association and its vision of a world without Alzheimer’s disease.
Remembering Judy

Judy’s grandchildren reflect on their grandmother

“Whenever I think of Granny, I am immediately brought back to her and Papa’s house in Palm Springs. I remember so many happy times with her in that house—running past her down the long hallway and narrowly avoiding the marble counter (I have no idea how I never hit my head on that thing), drawing pictures for her on yellow legal notepads at the kitchen table while eating grape nut cereal and drinking cranberry juice with ice, and swimming in the pool with her watching from the side (she never would come in). Wonderful memories that I will have forever. Thank you Granny. Love you, miss you.”

Brian Gelfand, 26

“While I’m sure I inherited my long legs and big feet from Granny, I didn’t think you could inherit a fashion-sense. I owe my fashion-loving and trend-savvy sense to Granny’s fabulous, Bob Mackey-wearing, self. Standing out in a crowd came naturally to Granny, and I only hope I can light up a crowd the way she did. I certainly owe the “beaded and sequins” section of my three closets to her (actually, I own all three closets to her)!

I love and miss her everyday, but I know there’s so much in me from her, so I’m so incredibly grateful, fortunate, and happy.”

Ilana Gelfand, 24

“W
herever I think of Granny, I am immediately brought back to her and Papa’s house in Palm Springs. I was truly a role model for us all, and continues to be for the entire Stearns/Gelfand lineage to come.”

Greg Stearns, 21

“My favorite memory of Gram would have to be me sitting on the island of our old kitchen while she held onto me and sang “she prettiest girl, I ever saw, was drinking Hoffman’s, from a straw…” I love thinking about every time this happened and being able to close my eyes and really feel her holding me and hear her voice singing.”

Jackie Stearns, 19

“Even though I was young, I still have distinct memories of Gran. Like Brian, I think of the beautiful house where she lived. Whether swimming in the hot sun, riding up and down the hallways on the toy bike they kept in their closet, or spending time with all my cousins, I was always having fun. I remember Granny watching as we played and keeping Papa from going crazy over the unsafe activities the grandchildren were doing. I will always miss Gran and even though I was only alive for her last years, it didn’t stop her from claiming a spot in my memories forever.”

Ben Gelfand, 17

“She prettiest girl I ever saw. I was drinking Hoffman’s, from a straw…”

Ella Stearns, 13

“Sophie has many loving wonderful memories of being with Judy. Her favorite ones are quite simple. She always loved visiting Palm Springs and getting to be with Judy in the home that she loved, and filled with love. Swimming in the pool, dancing and performing shows, picking grapefruits and listening and watching Judy play her piano. These are things that she will always hold close to her heart when remembering her grandmother Judy.”

Sophie’s (14) mom, Marcie Gelfand

“When I was four years old, my Gram died. Just before she died in her bedroom in Palm Springs, I was sleeping in the room next door. I heard a crying sound coming from her bedroom and ran in to see her. I jumped up to her bed and gave her a kiss on the cheek that sent her to heaven. That is my favorite memory of Gram.”

Ella Stearns, 13

“Drew was born at a time when Judy’s Alzheimer’s was definitely progressing. A memory for all of us was Judy’s final trip away from home. Marshall and Judy flew to San Francisco to be with us to celebrate Drew’s bris. I can vividly remember Judy in her beautiful yellow suit and big bright smile being there with us for this very special day. As always, she showed up and lit up the room with her presence. Drew will always be able to look at the photos from this day and know that his grandmother was there watching over him. That was Judy.”

Drew’s (11) mom, Marcie Gelfand

Sophie’s (14) mom, Marcie Gelfand

Sophie’s (14) mom, Marcie Gelfand

Sophie’s (14) mom, Marcie Gelfand
Reprinted from a story written by Elizabeth Gelfand Stearns for alzinfo.org, a new digital platform where women can report from the front lines of their own lives.

I’m a healthy, 52-year-old woman living an active, involved lifestyle, yet it’s not unusual for me to receive two or three panicked phone calls a week from friends and family my age. They call me because they’re afraid that they, or someone they care about, are losing their memory, afraid that this may be early symptoms of Alzheimer’s disease.

They call me because I run The Judy Fund, a family fund that raises and grants money to support Alzheimer’s research and public policy initiatives in partnership with the Alzheimer’s Association. Since I also sit on the national board of the Alzheimer’s Association (the leading non-profit health care organization that supports the care and cure of Alzheimer’s disease), I have access to a wealth of information and expertise on how to care for people with Alzheimer’s. This allows me to help and support and, when necessary, seek out experts who can professionally intervene.

These conversations with friends and family can take many directions — sometimes they result in connecting people with Alzheimer’s and families to resources that can bring them support. These conversations might also lead to raising the desperately needed funds to support further research that will lead to disease-modifying drugs or a cure.

People call me to get answers or be sent on a path for answers, and I’m generally a reliable resource for them. Except for one area — one very important question — at heart of this disease, especially for our generation of baby boomers: “Do you really want to know?”

There is a simple blood test you can take to find out if you can remove it. Everyone who gets Alzheimer’s will eventually die from it, unless some other disease takes him or her down before their brain has completely stopped functioning. That outcome certainly begs the question: Do you really want to know?

On some level, I’ve been too scared to want to know. But that leaves me feeling like a victim — and I do not want to be a victim of this disease. That has led me to a decision: I have asked my brothers to join me in a medical research study specifically designed for healthy adult children of Alzheimer’s. The Wisconsin Registry for Alzheimer’s Prevention (WRAP) is one of the country’s first and largest Alzheimer’s disease prevention research programs and is a part of the Wisconsin Alzheimer’s Institute’s Initiative at the University of Wisconsin-Madison. The primary goal of WRAP is to identify the genetic, lifestyle and environmental factors that eventually lead to the development of Alzheimer’s in families.

The information to be gained from WRAP is essential for early interventions that have the potential to slow the progression, delay the onset or even prevent Alzheimer’s. This longitudinal study can help unlock the future of Alzheimer’s survivorship through tracking the physical health and lifestyle patterns of groups of people through generations over time. We can look at The Framingham Study, which began in 1948 and identified major cardiovascular disease risk factors, including high blood pressure, high blood cholesterol, smoking, obesity, diabetes and physical inactivity. Framingham has led to the development of effective treatment and preventive strategies in clinical practice that now prevent and cure heart disease.

By enrolling in the WRAP study, I will choose to find out if I carry the APOE-e4 that could put me at greater risk of developing Alzheimer’s disease.

And I want to know. I’ve changed to be part of change. Since Framingham, hundreds of thousands of healthy adults from all over the world have actively participated in research trials that have led to survivorship for the major diseases of our lifetime. I want to be part of the generation that survives Alzheimer’s — and give that gift to future generations.

And to get to that goal, I need to know.

Elizabeth Gelfand Stearns

As chair of The Judy Fund, Elizabeth Gelfand Stearns works to ignite public awareness and engagement in the battle against Alzheimer’s disease. To date, The Judy Fund, created in memory of Elizabeth’s mother, Judy Gelfand, has raised and granted close to $5 million to support Alzheimer’s research and public policy. Elizabeth Gelfand Stearns was appointed to the Alzheimer’s Association National Board of Directors in 2011.

With My Grandson, Who I Am? With Maria Shriver (2009) —

Shriver walks a girl through acceptance of her grandfather’s Alzheimer’s and the beginning of understanding his condition.

The girl explores ways to help her grandfather — and herself — cope by creating a photo album of their times together.

The book is great resource to help younger children deal with how the disease affects their loved one and their family. Shriver has generously donated copies to the Alzheimer’s Association. It can be purchased at alz.org/shop, with proceeds benefiting the Association.

What’s happening to Grandpa?

Alzheimer’s disease advocate Maria Shriver, whose father, Sargent Shriver, passed away with Alzheimer’s in 2011 at the age of 95, wrote What’s Happening to Grandpa?, a 2004 children’s book about explaining the disease to kids. (It inspired the Emmy-Award winning segment of HBO’s “The Alzheimer’s Project” called “Grandpa, Do You Know Who I Am? With Maria Shriver” in 2009.)

In What’s Happening to Grandpa?, Shriver walks a girl through acceptance of her grandfather’s Alzheimer’s and the beginning of understanding his condition.

The girl explores ways to help her grandfather — and herself — cope by creating a photo album of their times together.

The book is great resource to help younger children deal with how the disease affects their loved one and their family. Shriver has generously donated copies to the Alzheimer’s Association. It can be purchased at alz.org/shop, with proceeds benefiting the Association.
“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
The Judy Fund Donors

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Your Dollars are Making a Difference
• Nearly $5 million raised by The Judy Fund to-date
• Ten research projects sponsored
• More than 430 Alzheimer’s Association Ambassadors sponsored
• Sponsored the Dartmouth Cost of Alzheimer’s Disease Study
• Sponsored the Lewin Cost Impact Study
• Partially sponsored the Alzheimer’s Study Group

The Judy Fund’s 2012 Walk to End Alzheimer’s® team raised more than $11,000, surpassing its $8,000 goal. Led by team captains Sophie Gelfand and Ella Stearns, the team was one of 300 that participated in the Los Angeles Walk, which raised over $530,000. The Judy Fund team will participate in the 2013 Walk to End Alzheimer’s® on Sunday, November 3. To join the team or donate, please visit alz.org/walk.
The Judy Fund 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 nearly $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.

The Judy Fund remembers a great friend and enthusiastic supporter, Sue Herzog. Sue and Judy shared decades of love, laughter and family. Sue’s energy and heart will be missed.

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.

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