Dear Friends and Family,

The Judy Fund has a fantastic partnership with the Alzheimer’s Association, which allows us to do the meaningful work we have done over the last 13 years. When our team sits down to develop, write and publish our annual Judy Fund newsletter, we spend time looking at themes and trends that are critical to my mission of engaging the public in the fight against Alzheimer’s disease. This year’s theme — “A Voice for Alzheimer’s” — allows us to shine a spotlight on the power of advocating for public policies to change the trajectory of this disease. There is no more important time than now to understand that power, when we have a unique opportunity to make our voices heard.

The good news is that this year you don’t need to look far to find stunning examples of the power that advocacy and public policy have to turn the tide against Alzheimer’s. Summer 2016 was a historic time in Alzheimer’s disease research funding, and you can read all the details in The Judy Fund’s interview with the Association’s Chief Public Policy Officer Robert Egge on page 2. Leading researchers say at least $2 billion a year in funding at the National Institutes of Health is needed to reach the first goal of the National Plan to Address Alzheimer’s Disease: to prevent and effectively treat Alzheimer’s by 2025. I remember attending the 2013 Alzheimer’s Association Advocacy Forum in Washington, D.C., and discussing the goal of increasing research funding — at that time a daunting thought, as funding was just over half a billion annually. Three years later, this figure has nearly doubled thanks to unrelenting advocacy efforts. We’re on our way!

What seemed impossible a short time ago is now a finish line that is within our reach. Thank goodness: just in time for the 78 million baby boomers who will be 65 and older in the next decade — entering an age of greater risk for developing Alzheimer’s. Without a breakthrough, more than one in three of these boomers will get the disease. This funding for research couldn’t come quickly enough.

How does all of this happen? The Association gives an important share of the credit to its Ambassador Program. This grassroots team of more than 500 volunteer Ambassadors nationwide is assigned to work in their home districts with their federal legislators to push the Association’s national policy agenda. The Association facilitates a high level of interaction between each Ambassador and their legislator. And who drives the Ambassador program? You do. You have enabled this monumental win. You are The Judy Fund.

The results of investment are clear: We have seen bipartisan support by our government officials in this fight. There are some outstanding legislative leaders who we have profiled in this newsletter, along with their volunteer Ambassadors and the Ambassador Program (see page 4). You can help us continue this important work by using the enclosed envelope or visiting alz.org/judyfund to make a donation.

I’ve learned a lot about Alzheimer’s over this past decade. But the best lesson is in understanding that we all can be a part of the solution. As Margaret Mead said, “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it is the only thing that ever has.”

Happy travels!

Elizabeth Gelfand Stearns
Chair
The Judy Fund
There is nothing more powerful than you.” That’s the message the Alzheimer’s Association public policy team sends to those impacted by Alzheimer’s disease. Sharing a personal story with a lawmaker, combined with compelling facts and a clear request, is one of the most effective ways to advocate for better policies. By speaking up and following this strategy, the Association’s advocates have advanced its public policy agenda dramatically, particularly over the past six years.

This year House and Senate committees showed bipartisan support by approving an additional increase for Alzheimer’s research funding at the National Institutes of Health (NIH) that could be as high as $400 million. If signed into law, this would be the single largest federal increase to date and would bring annual research funding for Alzheimer’s at the NIH to just under $1.4 billion, more than halfway to the at least $2 billion experts say is needed to make real progress toward prevention or treatment of the disease.

However, people often aren’t sure what advocacy is and how it drives legislation like this forward. Advocacy is action in support of a cause or proposal, like a new policy or law, and advocates are the people who seek to educate policymakers and enlist their help toward that goal. Anyone can be an advocate, whether they want to make an occasional call to an elected official’s office or meet with them or their staff on a regular basis.

To further explain the power advocates have to affect public policy, Alzheimer’s Association Chief Public Policy Officer Robert Egge answers some questions.

Q. Why should public policy be important to everyone who cares about Alzheimer’s disease?

Alzheimer’s disease is a big problem that requires a big solution. The biggest problem is what it does to the lives of individuals and families. But the costs due to Alzheimer’s also demand attention. Our nation will pay an estimated $236 billion this year in Alzheimer’s costs, and with someone developing the disease every 66 seconds, those costs will continue to rise year by year. Public policies have a broad impact on the research and care and support that help our cause, making federal and state governments critical allies in our fight against the disease.

Here is just one example of why government support is so essential to our fight, especially in securing research funding: The Alzheimer’s Association is the largest private nonprofit funder of Alzheimer’s research in the world. Since 1982, the organization has awarded over $375 million — including $25 million this year — to more than 2,400 best-of-field grant proposals. Because these are private funds, the Association itself decides how to use them flexibly and strategically to meet its objectives. Private dollars are essential to the Association’s work and complement other types of funding.

However, in almost every disease area, private dollars are generally much smaller than federal funding. The Association brings speed, agility and an international portfolio to Alzheimer’s research funding, but there is no substitute for the scale of support that Congress can deliver through the NIH. That’s why we have relentlessly advocated to raise NIH funding for Alzheimer’s research.

Q. How is advocacy making a difference in the fight against Alzheimer’s nationally?

Over the past six years, the Association and its advocates have made remarkable progress toward our public policy goals. An estimated 10,000 bills are introduced during each session of Congress, but only 4 percent, or about 400, make their way through the House and Senate and are signed into law by the president. The chance of getting a bill passed is very low in most cases, which makes the victories we have

Alzheimer’s research funding at the NIH has grown tremendously since 2011, thanks to the work of Association advocates and Ambassadors.
won all the more impressive. We are on track to achieve a third of our bills this year over a six-year stretch, and on top of this we have the funding increase.

As mentioned earlier, the gains in NIH Alzheimer’s funding are nothing short of astounding. Many experts told us several years ago that what we’ve accomplished simply wouldn’t be possible — it wasn’t realistic. Nevertheless, we went ahead and made increasing funding for Alzheimer’s research a top priority. We started setting our plan in motion with the creation and passage of the National Alzheimer’s Project Act (NAPA) in 2010. In 2012, when the National Plan to Address Alzheimer’s Disease was released by the administration as required by NAPA, it contained an additional $50 million for research. Since that time, we’ve made steady increases, including last year’s historic increase of $350 million, bringing total NIH funding for Alzheimer’s research to just under $1 billion.

Another top policy priority is improving access to care planning, which the Association and its advocates have worked to advance through the Health Outcomes, Planning and Education (HOPE) for Alzheimer’s Act. The HOPE Act would provide Medicare coverage for comprehensive care planning services for both the individual and his or her caregiver, following a dementia diagnosis. Care planning is crucial for improving outcomes for the individual, coordinating care and managing other chronic conditions, such as diabetes or heart disease. Support for HOPE has risen each year, but it’s never been stronger than today. In a major breakthrough, the Senate Appropriations Committee included the HOPE for Alzheimer’s Act in its fiscal year 2017 funding bill, and the Association is optimistic about its passage.

Q. How can people advocate for the Alzheimer’s movement?

People can get involved as Alzheimer’s advocates in several ways. First, visit alz.org/advocacy to learn about the issues and pending legislation. You can register as an advocate to receive updates and alerts informing you when you can take action by contacting your elected officials. The Association also has a sister organization, the Alzheimer’s Impact Movement® (AIM), a nonpartisan, nonprofit advocacy organization working in strategic partnership with the Alzheimer’s Association. You can learn more about AIM at alzimpact.org.

Second, connect with the Association in your community. You can locate the chapter closest to you by visiting alz.org/findus. We need everyone’s voice to help us defeat Alzheimer’s disease — and yours can be one of them. When advocates describe how Alzheimer’s has personally impacted them and propose solutions, lawmakers listen. We’ve seen that in the progress we’ve made, and can continue to make, with your help.

Q. How does state policy impact Alzheimer’s and how can advocates make an impact on the local level?

State Alzheimer’s disease plans provide a framework for fighting Alzheimer’s where people live, in their communities. Because of the scale of the Alzheimer’s epidemic, the costs to state budgets are a key concern. For example, Medicaid is a government program that uses a combination of federal and state dollars to pay health care expenses for low-income people. Medicaid is one of the largest items in state budgets, and the amount states allocate to pay for the costs of nursing home and other types of care related to Alzheimer’s are expected to grow tremendously in coming years as our population ages and more people are diagnosed with the disease. Across the country, Alzheimer’s Association advocates are working with their state governments to increase state Medicaid funding so people living with the disease and their families will have the services they need.

Training for health care professionals is another example of a state policy priority. Employees in residential, home and adult day settings must be properly trained in dementia care. Yet training standards vary widely. Less than half of states require dementia training for staff of nursing homes, and less than one-fifth of states require it for adult day staff.

California is one state that exemplifies good training practices. As of Jan. 1, 2016, all direct care staff at all residential care facilities for the elderly must have 12 hours of dementia care training, with six hours completed before the staff person begins working independently with residents. In addition, staff must participate in eight hours of training each year on serving people with dementia. These rules were put in place thanks in large part to the advocacy efforts of Association staff and volunteers at our six chapters in California.
The Alzheimer’s Association Ambassador program is a key player in advancing public policy and funding to fight Alzheimer’s. All of the recent policy and funding gains made by the Association have happened while the Ambassador program was expanding. The program started in 2010 with just 24 people; today it has grown to 511 Ambassadors. The goal is to reach 535, one for every member of Congress.

Ambassador Ron Grant of Oklahoma City was diagnosed with younger-onset Alzheimer’s at age 55. Knowing he was facing a disease for which there is no treatment or cure, he initially felt hopeless — a feeling somewhat foreign to the former chaplain of the Oklahoma Department of Corrections. Refusing to let Alzheimer’s silence him, Grant sought opportunities to fight the disease using one of his most powerful tools — his voice.

In 2013, Grant joined the Alzheimer’s Association Ambassador Program. Supported by The Judy Fund, the program is made up of advocate leaders who establish and cultivate relationships with local members of Congress and district staff, engaging them in several meetings each year. Ambassadors play a critical role in helping the Association meet its federal policy goals.

Grant serves as Ambassador to Rep. Tom Cole (R-Okla.), chairman of the House Appropriations Labor, Health and Human Services Subcommittee. To illuminate the issues surrounding Alzheimer’s, Grant shares his experiences with the congressman, offering a firsthand account of the disease that is destroying our nation’s families and finances.

Grant’s efforts have no doubt made an impact. Cole has emerged as a leading champion for the Alzheimer’s cause, strongly supporting the Association’s calls for increased federal research dollars and paving the way to a historic $350 million increase that was signed into law in the fiscal year 2016 budget.

“By supporting investments in Alzheimer’s research, Representative Cole is serving his constituents and our country in a very important way,” says Grant. “I’m proud to be his Ambassador.”

Myriam Marquez of Seattle was diagnosed with younger-onset Alzheimer’s at age 63. She joined the Ambassador program in 2014, working with Sen. Patty Murray (D-Wash.), ranking member of the Senate Appropriations Labor, Health and Human Services Subcommittee, and, like Cole, a vital force in securing the $350 million increase in research funding for FY16. Marquez, a former public defender and lobbyist, seeks every possible opportunity to inspire action.

“My name is a warrior doing whatever I can to bring us closer to a cure,” says Marquez. “I know I can count on Senator Murray to help drive that goal because she’s truly dedicated to this fight.”

To learn more about the Alzheimer’s Association Ambassador Program, visit alz.org/advocacy.

Alzheimer’s Champions on Capitol Hill

Sen. Patty Murray (D-Wash.)
- Spearheaded bipartisan effort to secure historic $350 million increase in federal funding for Alzheimer’s research at the National Institutes of Health in FY16.
- Secured bipartisan support for inclusion of proposed additional $400 million increase in federal Alzheimer’s research funding and passage of Health Outcomes, Planning, and Education (HOPE) for Alzheimer’s Act in the Senate Appropriations Committee funding bill for fiscal year 2017.

Rep. Tom Cole (R-Okla.)
- Championed a landmark effort resulting in a $350 million increase in federal Alzheimer’s research funding in FY16.
- Led bipartisan effort in House Appropriations Committee for additional $350 million increase in federal funding for Alzheimer’s research in FY17.
Judy Gelfand was my mother-in-law. We met, oddly enough, on a blind date.

I was living in New York and had been dating her daughter, Elizabeth, for a couple months. Judy was coming to New York for a visit with her cousin, Marsha. Elizabeth was spending the summer in Europe but suggested that I call Judy and go and introduce myself. So I called her and we set up a date; I picked her up and we drove to the River Cafe under the Brooklyn Bridge. On the way into the city, Judy asked me what music I liked, and I immediately popped in a cassette of a Grateful Dead show. While I know it wasn’t her cup of tea, she sure played along and we had a great drive and a great dinner … a memorable first date.

Judy loved convertibles. Every three years, she would trade in her Chrysler LeBaron convertible for a new one — always silver. She loved that car. Even in the middle of July in Palm Springs when the temperature would approach 120 degrees, Judy would put the top down and enjoy the sun. One sunny day, I was sitting in the back seat and not paying attention. The top came back with my arm slung over the seat and I thought the frame was going to snap my arm off. It crunched, I screamed! Judy reversed the motor, the top went back, and my arm was saved. We laughed about it many times over the years.

Judy was always positive, always happy and brought that out in anyone else who was nearby. The only time she ever got mad at me, it was her son Dean’s fault. One weekend in Palm Springs, I was “Deaned,” a family term for an argument with my brother-in-law, which is always pointless. The argument got physical. Dean threw my sneaker into the pool, and I was so mad, I grabbed his suit jacket and threw it in the pool, too. Of course, Judy came out at that very moment and all she saw was Dean’s only suit soaked and chlorinated and that I was the culprit. She was mad at me and let me know it. The anger did not last long, and I think Dean still has the suit.

Judy and I shared a love of music and pianos. She was classically trained at Juilliard, and I’m a hack who can noodle out just about anything. We would play together wherever there was a piano — in Palm Springs, in Malibu or in Santa Monica. For her 16th birthday, Judy was given the choice of a trip to Europe or a Steinway piano. She chose the piano and, while it has been three different colors over the decades, Judy’s piano sits proudly in our living room. At the end of her life, when she could not find any words, she could still sit down at the piano and knock out a Chopin etude.

Two of my lasting memories of Judy involve her struggle with Alzheimer’s. Judy used to drive around Los Angeles and knew the neighborhoods and directions quite well. One day, she was supposed to pick up a phone at a store she had been to a dozen times. She called me and complained that she was there but they had moved the store. I called the store and learned that it had not moved. She called me and complained that she was there but they had moved the store. I called the store and learned that it had not moved. I got frustrated and tried to guide her to the correct address. She eventually found it. At the time, I did not see that it was Alzheimer’s.

Judy enjoyed shopping in New England and going to the outlets with Elizabeth. I remember buying a jacket at L.L. Bean in Maine. It was a great lightweight blue jacket with a fleece lining. Judy, who was often cold, would borrow it when in Los Angeles. One day, I went to wear it and the jacket was gone. Ten years later, while cleaning out Judy’s closet, there it was! I took it home and still wear it today. When my kids wear it, like my daughter Jackie did recently, I tell the story and it reminds me of Judy.

Richard Stearns still plays Judy’s beloved Steinway piano, which has its permanent home in the Stearns’ living room. While Judy and Richard shared a deep love of music, he has substituted her Chopin etudes with songs by Eric Clapton and The Rolling Stones.
For the fourth consecutive year, the men of Sigma Alpha Mu (ΣAM) Fraternity have exceeded their previous year’s fundraising total for The Judy Fund, the fraternity’s national charity of choice since 2005. Last year, they broke $100,000 for the first time by raising $103,013. This past year, they raised a total of $132,740 through a variety of creative activities.

“Year after year, they continue to challenge themselves to do more for The Judy Fund, and they succeed,” says Elizabeth Gelfand Stearns, The Judy Fund chair. “More than $132,000 this year! We could not be more proud or grateful for their dedication to ending Alzheimer’s disease.”

“No Shave November II
The men of Sigma Alpha Mu “got growing” again in 2015 by participating in No Shave November (NSN) for The Judy Fund. Chapters and alumni groups around the country grew out their facial hair for the entire month and asked family, friends and others to sponsor their efforts. This year they garnered $41,771, motivated in part by a hair-raising incentive. The Gelfand Family and the Alzheimer’s Association offered to fly the top fundraiser and another Sammy — drawn in a raffle that included every brother who raised at least $100 — to Los Angeles to attend the 5th Annual Hilarity for Charity® variety show. Hilarity for Charity is a movement led by Alzheimer’s Association Celebrity Champions Seth and Lauren Miller Rogen to inspire change and raise awareness of Alzheimer’s among the millennial generation, so it is a perfect fit for Sigma Alpha Mu. Congratulations to Michael Dugan of the Mu Psi Chapter and Carl Gold of the Beta Iota Chapter, who attended Hilarity for Charity!

An Affair to Remember
This year, a ΣAM alumni group stepped up its commitment to ending Alzheimer’s in a major way. Led by Chairman Steve Stern, the South Florida Sigma Alpha Mu Alumni hosted “An Affair to Remember.” This yearlong fundraising effort for The Judy Fund culminated in a dinner at Stratford Court of Boca Pointe in Boca Raton, a senior living community. Overall, the group raised an astounding $31,913.

Sammies Attend Advocacy Forum
ΣAM chapters also host their own fundraisers. This year’s events included “Sammy Sweetheart” at Syracuse University, a competition among sororities to determine who would be the Eta Chapter’s “sweetheart.” The chapter raised an impressive $15,839 through the event, which also included a week of awareness activities on campus.

Nick Morrison (L) and Will Clarke (R) from the Mu Psi Chapter at Miami University of Ohio with Elizabeth Gelfand Stearns at the 2016 Alzheimer’s Association Advocacy Forum

To honor their chapter as top fundraisers, Gelfand Stearns welcomed Nick Morrison and Will Clarke from the Mu Psi Chapter at Miami University of Ohio as her guests at the annual Alzheimer’s Association Advocacy Forum. “With their passion for the cause, Nick and Will were great additions to the Forum,” Gelfand Stearns says.

Clarke chronicled his reflections on the Forum in a thank-you note: “My biggest takeaway from this forum was a sense of perspective. Even if you have all of the facts about Alzheimer’s, you will never be prepared for the stories you hear and the struggles people endure for their loved ones. I was also blown away by the incredible progression of the Alzheimer’s Association as a whole. Those four days were great and extremely educational.”
Moving the Cause Forward

Walk to End Alzheimer's

The Judy Fund was well represented at the 2015 Alzheimer’s Association Walk to End Alzheimer’s®. Led by Elizabeth Gelfand Stearns, the 41-member team, which included four generations of Gelfand and Stearns family members; Gelfand, Rennert & Feldman employees; Partners Trust employees; and other friends of The Judy Fund raised more than $6,000 to help advance the care, support and research efforts of the Association. To join The Judy Fund team this year, visit alz.org/thejudyfund.

The Judy Fund team has a counterpart in the Midwest. On Sept. 25, family friend David Berry and his team participated in Walk to End Alzheimer’s in Chicago. David’s mother has Alzheimer’s and he named his team after The Judy Fund in gratitude for the support and guidance he has received from the Gelfands. The group raised more than $5,000. Gelfand Stearns’ brother, Dean Gelfand, spent a summer with the Berry family in Chicago during college and describes David’s mother, Annette, as “a mom to us all.”

Women’s Alzheimer’s Research Initiative (WARI) Grant Awards

A year ago, the Alzheimer’s Association launched the Women’s Alzheimer’s Research Initiative (WARI) to advance studies on gender differences in Alzheimer’s disease and other dementias. The Judy Fund is directly supporting WARI, which recently announced its first set of research awards to nine studies — eight in the United States and one in Italy.

Though longevity and lower death rates can explain in part why women are at a higher risk than men to develop Alzheimer’s, many fundamental questions remain. Understanding gender differences in the development of the disease is critical to the health of our nation and the world.

The data gleaned from these studies will catalyze important discoveries about Alzheimer’s disease in women and men alike. Your support of The Judy Fund will help to advance progress in this critical area of research.

On May 21, 2016, Maria Shriver and Equinox sports clubs held Move for Minds®, a groundbreaking national event to raise awareness and funds to support women’s brain research, including WARI. “Women are at the epicenter of the Alzheimer’s crisis, which is why we must be at the heart of the solution,” Shriver says.

Recognizing an Alzheimer’s Hero

In June, Elizabeth Gelfand Stearns had the honor of presenting California State Sen. Ben Allen (D-Santa Monica) with the 2016 Legislator of the Year Award at a gathering of over 200 Alzheimer’s advocates representing the entire state. Gelfand Stearns is a constituent in Allen’s district and has worked with him on legislation to advance the fight against Alzheimer’s.

As a freshman senator, Allen distinguished himself as a champion for the 610,000 Californians living with the disease and the 1.5 million family members and friends who provide care and support to them by introducing Senate Bill 613, a measure requiring an update to California’s outdated physician guideline for Alzheimer’s disease management.

alz.org/judyfund
The Alzheimer’s Association and The Judy Fund recognize Sen. Barbara Boxer (D-Calif.) for her strong support of public policy addressing the Alzheimer’s epidemic. Boxer, who will retire after finishing her current term in Congress, co-sponsored the National Alzheimer’s Project Act (NAPA), which passed Congress at the end of 2010. She is a current co-sponsor of the HOPE for Alzheimer’s Act, and she previously co-sponsored this legislation in the 112th Congress and the 113th Congress. Boxer is also a longtime member of the Congressional Task Force on Alzheimer’s Disease. She was first sworn in to the Senate in January 1993 and is currently serving in her fourth term. Prior to her time in the Senate, Boxer served five terms in the U.S. House of Representatives.

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 Gelfand and Elizabeth Gelfand Stearns established The Judy Fund in 2003 in loving memory of Judy Gelfand. Since its inception, this family fund has raised more than $6 million in support of the Alzheimer’s Association. The Judy Fund is relentless in its efforts to prevent this disease from striking future generations.

Your support has enabled The Judy Fund to finance public policy efforts and vital research grants. Thank you for joining the Gelfand family in helping to advance the mission of the Alzheimer’s Association.

Visit alz.org/judyfund to see a listing of donors to The Judy Fund.