Dear friends and family,

In this year of profound change, 600 Alzheimer advocates from across the country traveled to our nation’s capital to be part of the 2009 Alzheimer’s Association Public Policy Forum. We arrived in late March, while there was still a nip in the air and the cherry blossoms were beginning to bloom.

The momentum that has swept through Washington, D.C., in recent months can also be felt in the battle against Alzheimer’s disease. Several key factors are emerging at once, allowing us to bring the movement to light: The baby boomer generation is approaching age 65, the age of great risk for developing Alzheimer’s; stories of younger-onset (people developing the disease under age 65) are becoming more abundant; and those already diagnosed with Alzheimer’s have emerged with a voice of their own.

To start the week, the Association held an Early-Stage Summit to focus on individuals who are managing the beginning phases of the disease. Attendees heard from keynote speaker Lisa Genova, author of the Alzheimer-focused novel Still Alice and a significant new voice in the Alzheimer community. If you haven’t read her book, I encourage you to go out and purchase a copy – it will certainly change the way you think about Alzheimer’s disease.

Of the many highlights of our week in Washington, two stand out as defining moments for me. On March 24, I was honored to be the mistress of ceremonies at the Forum’s candlelight vigil, held on the steps of the Lincoln Memorial. Standing in the shadow of one of our greatest leaders, hundreds of advocates gathered to honor those lost to Alzheimer’s. As dusk turned to night, we lit individual candles to form a sea of twinkling lights along the Reflecting Pool that spans the distance from the Lincoln Memorial and the Washington Monument. This trail of light honored the fact that we can – and we must – remember.

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Maria Shriver, first lady of California, was in the audience that evening, and lit and held a candle to honor her father Sargent Shriver. She is now forever part of this community of change.

The next day we traveled to the Dirksen Senate Office Building for a standing-room-only hearing. We heard former Speaker of the House Newt Gingrich, former Senator Bob Kerrey, former Supreme Court Justice Sandra Day O’Connor and Maria Shriver testify before the Senate Committee on Aging to unveil results of A National Alzheimer’s Strategic Plan, a report released by the Alzheimer’s Study Group. This unprecedented report, supported by the Alzheimer’s Association, provides national facts on the disease and paints a picture of its horrifying impact on American families, our health care system and, ultimately, the economy. Shriver gave a moving testimony about her father’s struggle with the disease that resonated with many in the audience.

The remainder of the week included training sessions with Association staff and meetings with legislators to advocate for research funding. The week’s events culminated in a celebration at the Alzheimer’s Association National Gala. Held in the historic Building Museum, the gala draws Alzheimer philanthropists, ambassadors, senators and congressmen together to recognize our progress in the fight against Alzheimer’s. French President Nicolas Sarkozy was honored for adopting an Alzheimer plan in his country and setting an example for the rest of the world to follow. Senator Jay Rockefeller and Sharon Percy Rockefeller received the Sargent and Eunice Shriver Profiles in Dignity Award, presented by Maria Shriver.

What a fantastic week of change! You can be a part of this movement by supporting The Judy Fund and signing up to be an Alzheimer’s Association advocate. Your gift will help to usher in a new era in Washington – an era in which research funding will ultimately create a generation of Alzheimer’s disease survivors.

“I have to say that the last 48 hours have probably been the most moving 48 hours of my life.”

First Lady of California Maria Shriver, reflecting on the Alzheimer’s Association Public Policy Forum and related activities

Elizabeth Gelfand Stearns
Chair
The Judy Fund
Advocating for change

The Alzheimer’s Association hosts Public Policy Forum in Washington

The Alzheimer’s Association 21st annual Public Policy Forum was the headlining event in a week of activities that captured America’s attention and exposed the growing threat of Alzheimer’s disease. On March 23-25, Alzheimer advocates from a record number of states and congressional districts gathered in Washington, D.C. to send a critical message to our nation’s leaders: Make Alzheimer’s disease a national priority.

Advocates attended workshops and panels about significant research updates, methods for community engagement and the effect of the new administration on the political landscape. Advocates also received training and talking points to prepare for meetings with members of Congress.

Representing 49 states, these inspiring individuals made their presence known by meeting with legislators to advocate for increased research funding, the establishment of the Alzheimer’s Solutions Project and dissolution of Medicare’s two-year waiting period for people under age 65 who are disabled. In total, Alzheimer advocates made an unprecedented 462 visits to congressional offices, garnering additional support for the cause in the political arena.

A discussion on early-stage Alzheimer’s
To begin the week’s activities, the Association hosted its first national Early-Stage Summit on March 23. This targeted event attracted an audience of 200 attendees, comprising mainly individuals living with early-stage Alzheimer’s and their caregivers. Featuring keynote speaker Lisa Genova, author of the best-selling Alzheimer-focused novel Still Alice, the event built a platform for the discussion of key issues including the importance of a dignified diagnosis and increased access to clinical trials. Additionally, the Summit helped fuel Forum activities, activating the largest crowd of people with dementia ever to attend as key advocates.

Illuminating the cause
To conclude the first day’s events, Alzheimer advocates, including veteran journalist and First Lady of California Maria Shriver, gathered on the steps of the Lincoln Memorial to share stories and light candles in honor of loved ones affected by Alzheimer’s disease. Elizabeth Gelfand Stearns, Alzheimer Champion, advocate, donor and co-founder of The Judy Fund, served as emcee for this moving Candlelight Vigil. In addition, more than 500 advocates participated in a virtual vigil on alz.org by lighting “candles” to honor a loved one or show support for the fight.

“This unyielding call for change resonated throughout the Forum and the week’s other activities, as those leading the fight against Alzheimer’s took awareness to a new level.

“Our nation is certainly ready to get deadly serious about this deadly disease.”
Retired Supreme Court Justice Sandra Day O’Connor
Two groundbreaking reports reveal the state of Alzheimer's

On March 24, the Association released 2009 Alzheimer's Disease Facts and Figures to coincide with the media attention surrounding the Forum. This benchmark report about the incidence of Alzheimer's helped to launch a national conversation about the disease, capturing public interest and consuming the airwaves.

The 2009 report details the shocking health care costs associated with Alzheimer's, focusing on expenses for Americans aged 65 and older. Studies show that Alzheimer's disease triples health care costs for this subset of Americans – the same group at the greatest risk for being diagnosed. With a new case every 70 seconds and as many as 5.3 million Americans living with the disease, Facts and Figures clearly demonstrates that Alzheimer's disease is the public health threat of the 21st century.

Alzheimer's Association President and CEO Harry Johns had the opportunity to discuss findings from Facts and Figures on C-SPAN “Washington Journal.” Other significant media coverage included segments on ABC “World News Tonight with Charles Gibson,” “Nightline,” NBC “Nightly News,” CNN “Headline News” and NPR “Talk of the Nation.”

The Alzheimer’s Study Group (ASG) also released its report, A National Alzheimer’s Strategic Plan: The Report of the Alzheimer’s Study Group during the course of the Forum. Originally called for by the Alzheimer’s Association and the Joint Congressional Task Force on Alzheimer’s, the ASG is a non-partisan, blue-ribbon panel of national leaders created to assess the nation's readiness to deal with the Alzheimer crisis and develop a national strategic plan. Co-chaired by former House Speaker Newt Gingrich and former Nebraska Senator Bob Kerrey, the group’s report explains the looming crisis created by Alzheimer’s disease and offers real solutions for the nation. The Alzheimer’s Association funded much of the report and will play a leading role in seeking the enactment of the core recommendations.

“Many [caregivers] are forced to quit jobs to stay home – or go through the wrenching process of sending the parent away to a facility – feeling judged and mortified and ashamed that they can’t care for their loved one themselves. For so many, the financial, emotional and spiritual cost is just way too much to bear.”

Maria Shriver, First Lady of California
A standing-room-only senate hearing
The Association also participated in a hearing of the Senate Special Committee on Aging, where members heard from Newt Gingrich, Bob Kerrey, Maria Shriver and retired Supreme Court Justice Sandra Day O’Connor about the ASG’s recommendations for tackling the crisis of Alzheimer’s on a national level. The hearing was standing-room only as advocates packed the room to ensure that their message was heard on Capitol Hill.

Celebrating at the National Alzheimer’s Gala
As a conclusion to the Public Policy Week, many of our country’s philanthropic, corporate, social and political leaders came together for a night of celebration and recognition. On March 25, these noted supporters gathered at the 6th annual National Alzheimer’s Gala. Held at the National Building Museum, the gala is one of Washington’s most prominent events, attracting more than 750 people each year to build awareness of Alzheimer’s as a national priority.

This year, the gala honored individuals who have contributed to leading research in treatment, prevention and an eventual cure for Alzheimer’s disease, as well as ongoing caregiver and awareness efforts. The evening celebrated his Excellency Nicolas Sarkozy, the president of France; the Honorable Jay Rockefeller and Sharon Percy Rockefeller; William E. Klunk, M.D., Ph.D; Chester A. Mathis, Ph.D, University of Pittsburgh; and Terrell Owens, wide receiver for the Buffalo Bills. Alzheimer’s Association celebrity Champions Maria Shriver, Chris Matthews, Coach Frank Broyles, Phyllis George and Lea Thompson also lent their voices and passion to the evening’s program.
From July 11-16, the Alzheimer’s Association 2009 International Conference on Alzheimer’s Disease (ICAD) drew nearly 3,800 international attendees to Vienna. Together, this unique group of Alzheimer experts discussed the latest ideas, thoughts and theories in dementia science while learning from their peers.

To open the meeting, Alzheimer’s Association President and CEO Harry Johns confirmed the Association’s commitment to international research, including fellowships for ICAD attendees around the globe, our ever-growing grants program and the development of ISTAART, the International Society to Advance Alzheimer Research and Treatment, now with more than 1,500 members. These contributions have solidified the Association’s place as the leader in Alzheimer research worldwide.

ICAD provided its global guests with an unmatched collegial experience and unparalleled access to top-level, cutting-edge research. Looking ahead to ICAD 2010 in Honolulu, the Association is energized to continue these steps toward a shared vision of a world without Alzheimer’s disease.

Celebrity Champion Seth Rogen Joins QUASH®

At the 2009 Academy Awards®, actor Seth Rogen walked the red carpet with a meaningful accessory: his Alzheimer’s Association lapel pin. The star of “Knocked Up” and “The 40-Year-Old Virgin” has joined other celebrity champions in the fight against Alzheimer’s by helping to raise awareness. In April, Rogen extended his support by participating in the Alzheimer’s Association San Diego QUASH event. Now in its second year, QUASH is a citywide scavenger hunt that strives to bring a new generation to the cause while raising money for Alzheimer care, support and research. To help promote the event, Rogen did several interviews with area media, including The San Diego Union Tribune and KHTS-FM. Rogen’s team, Memory Finders!, raised more than $16,000 for the Association.
The Alzheimer's Association is deeply grateful to the following individuals, families, companies and organizations who have so generously supported the founding and growth of The Judy Fund.

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“Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has.”
Margaret Mead
The first time I met Judy Gelfand was at her engagement party. Her soon-to-be husband, Marshall Gelfand, and my late husband were fraternity brothers at Syracuse University. I remember the moment Judy opened the door to greet us. I was wearing a grey silk shirtwaist dress and at 5 feet, I resembled a small grey sparrow. She was wearing gold lamé toreador pants, a matching sleeveless tank top and 5-inch high strappy gold heels. To complete her larger-than-life image, her blond hair was piled high on top of her head. She looked sexy and fabulous. I hated her! But she welcomed me with genuine warmth.

"You must be Joan, I've heard so much about you," she said. My mouth dropped open. How could Marshall, a "hayseed" from Claremont, N.H., be marrying this glamorous girl from New York? I was surprised to later discover that Judith was a graduate of The Julliard School and had worked as a high school music teacher.

In the coming years, I discovered many other surprises about Judith. She treasured her friends. She had a "Joan file" where she put every letter and every poem that I ever sent her. I always started my letters to her, "Judith, it’s Joanith." One year for my birthday she sent me a bound book of my work and inscribed it with my special greeting for her.

Judy’s humor and thoughtfulness were without bounds. During my first trip to Palm Springs to visit her, she met me at the airport with a large printed sign that read, “Welcome Joan.” A huge group of children with flowers were there to greet me. I felt like a movie star.

That evening she had another surprise in store for me. I previously mentioned to Judy that I had never eaten a taco, so she took me to Taco Bell for a dinner party. She had arranged to rent the restaurant for a few hours, and set the tables with candles, crystal, china and flowers. The place was filled with friends both old and new. We had a ball! The kids behind the counter are probably still stunned.

Every summer, Judy and Marshall would rent a home in Malibu and invite me to visit. I called it “the Boo.” Judith filled our days with beach walks, exercise, massages and dinner parties. She made plans to the “nth” degree.

One year we had a party with a luau theme and Judith insisted that we needed palm fronds for the table mats. She concocted a plan to get them that involved my help. Like Lucy and Ethel, we piled into her LeBaron convertible and took off down Pacific Highway. Each time she spied a palm frond low enough for me to cut, she would stop the car, hand me a pair of scissors and order me into the back seat. When I suggested that it might be illegal and we could get stopped by the police, she laughed and told me not to worry.

"I'm driving the getaway car, and besides, my husband is a lawyer and can spring us from jail," Judy said. You gotta love a girl like that.

Our times together are engraved in my memory – I remember our hilarious exploits on trips, the times she insisted on reading aloud and her interest in Jackie Kennedy, Tina Turner and Marilyn Monroe.

As Judy’s memory faded, my memories of our times together have only become more precious. They are part of her gift to me. They are part of my life forever.

As far as Joan Mendelson is concerned, there were a few great things that came out of Syracuse University. While most of the world would scream Jimmy Brown, Joan would not. She would, however, tell you that Herb Mendelson, her husband of 40 years, and his friendship with Marshall Gelfand rank up there – and because of Marshall, Judy. For Joan and Judy, it was instant friendship – the beginning of a relationship that endured both distance and time. Joan’s memories of Judy and the joyous times they shared are a cherished part of Mendelson family lore.
The Alzheimer’s Association releases an unprecedented tool to aid in diagnosis

The Alzheimer’s Association has released an innovative *Principles for a Dignified Diagnosis* brochure that contains insights about the diagnosis experience from people living with Alzheimer’s. It is the first statement of its kind written by people with the disease.

*Principles for a Dignified Diagnosis* evolved from the rich dialogue at the Association’s 2007-2008 Town Hall Meetings, held across the country to discuss the challenges of Alzheimer’s disease. These gatherings drew a wide audience of medical professionals, community leaders and those living with dementia and their caregivers. The Town Hall conversations resulted in the identification of several common themes, including diagnostic challenges and unsatisfying interactions with the medical community.

After studying the feedback from the meetings, the Association worked in conjunction with the Early-Stage Advisory Board to develop the *Principles* brochure. The document is designed for people who are facing a diagnosis and who already may suspect that “something is wrong.” It lists simple requests that the person should ask of their doctor and caregiver, such as “Tell the truth” and “Speak to me directly.”

“Some of these requests may seem obvious,” said Shelly Bluethmann, director, early-stage initiatives, Alzheimer’s Association. “However, they speak to problems that can occur during the diagnosis process. Our hope is that the *Principles* brochure will empower people to seek a diagnosis that is as early and as dignified as possible.”

Dr. Steve Hume, a member of the Association’s Early-Stage Advisory Group and a co-author of *Principles for a Dignified Diagnosis*, was diagnosed with younger-onset Alzheimer’s disease in May 2007 at the age of 61. Dr. Hume was a clinician, consultant and senior manager in the behavioral health field, but despite his professional health background, he struggled to secure a complete diagnosis. In fact, the first neurologist he visited told him he’d be fine if he just lost weight.

“The face of Alzheimer’s has changed in recent years, and *Principles for a Dignified Diagnosis* adds a voice to that face,” said Dr. Hume. “It is important that we not only tell clinicians we want a dignified diagnosis, but also teach them what that means. There is a lot we can learn from each other.”

For reliable information and support, contact the Alzheimer’s Association:

1.800.272.3900
www.alz.org

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Principles for a Dignified Diagnosis poster
Do you know the 10 signs?

Are you familiar with the warning signs of Alzheimer’s disease? Unfortunately, most Americans are unaware that behavioral changes like decreased judgment, difficulty in completing tasks and withdrawal from activities may be signs of Alzheimer’s disease.

In an effort to educate the public, the Alzheimer’s Association has launched “Know the 10 Signs: Early Detection Matters,” an unparalleled campaign designed to heighten awareness of the warning signs of Alzheimer’s disease and explain the benefits of early detection and diagnosis.

“Know the 10 Signs” encourages Americans to seek a diagnosis from a doctor if they exhibit any of the warning signs. Early diagnosis allows individuals to consider treatment, plan for the future and enroll in clinical studies.

Funded in part by proceeds from the 2008 American Express Members Project, “Know the 10 Signs” television advertising launched on CBS stations May 17. Coverage included segments on the “The Early Show” on May 18, May 20 and May 22 with Dr. Jennifer Ashton, who reviewed the 10 signs and explained them to viewers. Interviews with Alzheimer’s Association Early-Stage Advisors and caregivers further illustrated the signs through real-life experiences.

Educational materials related to the campaign are now available at www.alz.org/10signs. In the upcoming months, workshops will be held in communities across the country in order to reach a wider audience. Corporations are joining the effort by enrolling in the Alzheimer’s Early Detection Alliance (AEDA) as a way to educate their employees and customers. The Alzheimer’s Association hopes that through these actions, we will empower individuals to make important choices about their own health and future.

For more information about the benefits of early detection and the warning signs of Alzheimer’s disease, visit www.alz.org/10signs or call our toll-free line at 877-IS IT ALZ (877.474.8259).

advertisement listing the 10 warning signs of Alzheimer’s disease.
During his time at the University of Pennsylvania, Brian made his mark as a philanthropist, leading his fellow Sigma Alpha Mu fraternity brothers in a creative fundraising effort for The Judy Fund. The Sammies, as the fraternity is widely known, hosted a charity poker tournament on campus in February.

“We wanted to create an event that would help raise money for The Judy Fund and promote awareness of Alzheimer’s at the same time,” said Brian, who graduated from Penn in May. “The other objective was to make it fun and enjoyable for students. A charity poker tournament seemed to fit the bill.”

The tournament attracted 150 students and raised more than $2,400 for The Judy Fund. With the help of a casino entertainment company, the brothers transformed one of Penn’s halls into a Vegas casino, complete with green poker tables and well-trained, tuxedo-clad Sammy pledges dealing out cards and chips to players. They secured sponsorships from a number of local businesses and enlisted the assistance of sororities Sigma Kappa and Chi Omega to sell concessions.

“We hope to continue this tradition and make the poker tournament an annual event,” Brian said. “Of course, our goal will be to increase revenue each year.”

Marshall Gelfand was extremely proud of his grandson’s success. A Sigma Alpha Mu alumnus himself, Marshall was instrumental in forging the partnership between the fraternity and the Alzheimer’s Association. Since adopting the Association as its national charity in 2006, Sigma Alpha Mu chapters across the country have hosted hundreds of fundraising events in support of The Judy Fund. They raised nearly $25,000 last year, and Marshall is hoping additional chapters will increase their efforts to organize events like the one at Penn.

Marshall has also issued a challenge to the Sammies. “Next year, if they can double the $25,000 they raised this year, I’ll match it with a $25,000 donation to The Judy Fund in the name of the fraternity,” said Marshall.

As the Sammies prepare to rise to the challenge in the upcoming school year, Brian has gone on to pursue a career in business. Much like his grandmother, he has helped leave behind a legacy of giving at Penn. No doubt Judy would be proud.

**THE ALZHEIMER’S PROJECT** airs on HBO

On May 10-12, the HBO documentary “THE ALZHEIMER’S PROJECT” aired to widespread critical acclaim. Promoted as the “film that will change the way America thinks about Alzheimer’s disease,” this four-part series was the result of years of interviews and collaboration among several partners: HBO Documentary Films and the National Institute on Aging at the National Institutes of Health in association with the Alzheimer’s Association, The Fidelity® Charitable Gift Fund and the Geoffrey Beene Gives Back® Alzheimer’s Initiative.

Featuring researchers and families who are involved with Alzheimer’s Association, the film uses multiple perspectives to paint an intimate portrait of Alzheimer’s disease in America. Stories and testimonials from those living with the disease, caregivers, children and scientists reveal how deeply Alzheimer’s affects the nation – and the reasons why we must work together to find a cure.

Embraced by the television critics and the public, “THE ALZHEIMER’S PROJECT” received rave reviews for its tough-but-realistic look at Alzheimer’s disease. Media highlights include an article on the front of The New York Times Weekend Arts section, a segment on “Good Morning America” and an interview on “Larry King Live” with First Lady of California Maria Shriver, one of the film’s co-producers. Alzheimer’s Association message boards saw a flurry of activity as those affected by the disease gathered online to discuss the films.

In order to help promote the documentary, the Association will hold nearly 90 community screenings nationwide by the end of the summer. These gatherings provide an outlet where local residents can watch the films together and ask questions in front of a panel of experts. The films can also be viewed free of charge at www.alz.org/hbo or purchased at www.alz.org/shop.

On Aug. 1, the series was honored with a Television Critics Association Award for Outstanding Achievement in News and Information. It has also been nominated for three Emmy® Awards. Winners will be announced on Sept. 21.
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 $3 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 various vital research grants, including the Association’s flagship grant, the Pioneer Award, in 2004. Thank you for joining the Gelfand family in helping to advance the mission of the Alzheimer’s Association.

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