

FALL 2005
SECOND
EDITION

The Judy Fund News

A newsletter published exclusively for our friends and supporters

Dear Friends and Family,

The first issue of **The Judy Fund** newsletter arrived one year ago. Since then, a lot has happened. On July 13, 2004 Judy Gelfand died of Alzheimer's disease. Her horrendous nine year struggle has become the catalyst for many powerful and positive things. Judy's legacy of engagement could not be better exemplified than by the great work of our Fund. Over the past 36 months, **The Judy Fund** has raised and granted over \$2.4 million to Alzheimer's research. Our money has come from family and friends, business colleagues and corporations. This money has been granted to medical researchers to ignite studies ranging from the smallest beta-amyloid tangles to a landmark study developing best-practices for the care of Alzheimer's patients.

We know that the answer to finding a cure to manage the catastrophe of Alzheimer's disease lies in both fundraising and awareness-raising. The fundraising answer is clear – this disease needs more money. Today, the federal government, through the National Institutes of Health, allocates \$649 million annually to fund Alzheimer's research. This is compared to the \$5.6 billion allocated for cancer, \$2.1 billion for heart disease and \$3 billion for AIDS. The impact of these funds is clear: cancer, heart disease, and AIDS patients have a variety of early detection and treatment therapies that can sustain their lives, along with ensuring a better quality of life. Alzheimer's funding needs to catch up quickly – in the next decade tens of millions of people in the U.S. alone will depend on it.

Can Alzheimer's have a beautiful face?

We have also been focused on awareness-raising. How do we engage the public in meaningful dialogue around this horrible disease? Can Alzheimer's have a beautiful face?

One answer became clear through some strategic work done

by Director/Producer Dan Curtis and Marshall Gelfand. We were able to license the recording and publishing rights to Barbra Streisand's classic song, *The Way We Were*, for the Alzheimer's Association. We produced a visual campaign using this powerful song to underscore the imagery of a life of memories.

The words and the music are now a beautiful and moving anthem of this disease. Look for the Public Service Announcements on local TV stations and at Alzheimer's Association functions.

Finally, we are convinced that we can build awareness of this disease through partnerships and storytelling. One unique partnership that we are most proud of is with our friend and colleague, Leeza Gibbons. Read Leeza's beautiful story on page two of this newsletter.

Thank you for all of your support. Please continue to give and stay involved with us. I know the rewards will be rich. They already are.

Elizabeth Gelfand Stearns

*Chair
The Judy Fund*

SAVE THE DATE

Friday
November 18th

*Marriott's Rancho
Las Palmas Resort & Spa
Rancho Mirage, CA*

Memories
A Judy Fund Gala

See page 7 for details

“Memories are precious. They're our continuity and what ties us to every one and everything we love. But I've seen how Alzheimer's can steal away these most personal and treasured possessions. I'm pleased that my music can be part of the effort to address and perhaps some day defeat a terrible disease.” ~Barbra Streisand

A Daughter's Promise

by Leeza Gibbons

THE KIDS ARE STILL OUT OF SCHOOL for the summer. In many respects, life goes on at a slower beat. My mother loved the more leisurely pace. "Why are you in such a hurry, darlin'?" she'd say to me. I wish I could tell her now what propels me forward with such a sense of purpose.

It's interesting to me how comforting the little things are. Every time I have an iced tea, I think of her. When I tuck my kids in at night and sing "Que Sera," I think of her. The breeze off the ocean as I write this seems somehow wise with her intention. These days, my mother's spirit is found in almost all the moments that define who I am. I am my mother's daughter; the keeper of her legacy; the eternal flame of her perpetual hope, the truth that guided her towards grace.

Six years now and I still find it catches in my throat to say Alzheimer's disease. It's like honoring a thief and succumbing to its power. When my mother was diagnosed with the same mind-robbing disease that took her mother's life, she was the brave one. She was the one who forced us to admit that this uninvited stranger had found its way into our family. And yet Alzheimer's wasn't a stranger at all, rather the inevitable threat we had managed to keep at bay until it rewrote every chapter of my mother's life and delivered to us a woman who was both frightening and pitiful.

Now I am a soldier in a reluctant army of daughters, sons, siblings, husbands and wives. All of us ashamed to admit how afraid we are and how powerless we sometimes feel; but only *sometimes*...

Most of the time I focus on what miracles await us in the near future and what progress we will make until they present themselves. Most of the time I can find reasons galore to forge into a time ripe with the promise of treatments, vaccines and even cures.

Until we get there, I am committed to doing what I can to offer comfort and care through the Leeza Gibbons Memory Foundation. I formed it in 2002 with my friend Jamie Huysman as Mom was fading deeper behind the veil of Alzheimer's disease. She made me promise her that I would "take her story and make it count." I



I am my mother's daughter; the keeper of her legacy; the eternal flame of her perpetual hope, the truth that guided her towards grace.

began to fulfill that promise by opening Leeza's Place; intimate, safe settings within communities to help families gather strength for the challenging journey ahead after diagnosis. The newly diagnosed and their caregivers find solace, support and services in a setting where dignity and respect are the guiding forces.

Part of our mission is to hold hands with other groups and organizations that are on the same path to a world without memory disorders. For years I have worked with the Alzheimer's Association and when I met Elizabeth Gelfand Stearns and learned of **The Judy Fund**, I knew I had found a sister in the fight. Elizabeth and her family have had a tremendous impact on Alzheimer's disease research and education. Elizabeth and I both know that families like ours, and many of you reading this,

have a powerful story to tell; a story that can prompt action.

Mom is dying in slow motion, but her will is strong. She told me, "You're a storyteller, honey, now tell THIS story." I am passionate about doing just that and am blessed to have so many allies along the way. I know my Mom will forgive me when I tell her I am *still* in a hurry, only now the sense of urgency is to make sure that my kids don't have to tell the same story about me that I share with you about my Mother and Grandmother. ■



Leeza and Elizabeth's stories are all too familiar. Both have endured their grandmothers and mothers' battles with Alzheimer's disease. They are united in a common mission to eliminate Alzheimer's for their children and for generations to come.

Leeza Gibbons is America's quintessential storyteller having been a popular radio and television personality for two and a half decades. Now she's been entrusted with the most important story of her life: her family's struggle with Alzheimer's disease. Leeza formed The Leeza Gibbons Memory Foundation and began to open Leeza's Places across the country offering comfort and care for those newly diagnosed with any memory disorder and for their caregivers. For more information on The Leeza Gibbons Memory Foundation please visit <http://www.leezasplace.org>.

The Judy Fund Research Award Update:



Edward H. Koo, MD

Background

Dr. Edward Koo of the University of California at San Diego was inspired by two of his medical school teachers to dedicate himself to Alzheimer's research. After working in the field for almost 20 years, his patients help reinforce his commitment. Dr. Koo is not only a successful basic scientist, but he is also a clinician who regularly sees Alzheimer's patients.

Progress Report

Through the support of **The Judy Fund** Research Award sponsorship, Dr. Koo aims to make greater headway in unraveling the mysteries of the amyloid hypothesis. His one year pilot study focuses on the effect of amyloid precursor protein (APP), the parent molecule of beta-amyloid, on gene activation. Although preliminary findings do not show a link between APP and gene activation, work is still underway to examine this relationship. Understanding the role of APP in normal cell function could have great implications for Alzheimer's drug treatment development. ■

—Nicole Clifford

2004

Progress and Hope in Alzheimer Science

Most of what we know about Alzheimer's disease we've learned in the last 15 years. The Alzheimer's Association is gratified to report that developments in 2004 added important insights to our growing body of knowledge. We saw gains in all the areas critical to sustaining the momentum of recent progress: discovering effective preventive strategies; achieving earlier diagnosis; developing better ways of measuring response to experimental drugs; improving treatments; and enhancing care and support for those living with the disease.

Prevention

Most experts agree that prevention will offer the most effective weapon in our long-term battle against dementia. The Alzheimer's Association has taken the lead in this vital arena by establishing and planning the first-ever International Conference on Prevention of Dementia. The inaugural Prevention Conference in June 2005 generated over 300 million media impressions as print and broadcast outlets worldwide reported the latest news on experimental treatments, lifestyle risk factors and other key findings.

Another major new prevention initiative is the Alzheimer's Association Maintain Your Brain campaign. This public health and education campaign, based on the best available scientific evidence, encourages all Americans to understand steps they can take now to make brain health part of their overall goals for healthy aging; to learn about Alzheimer's disease, recent progress in research and our new reason to hope; and to get involved with the Alzheimer's Association.

The Alzheimer's Association gained an additional important opportunity to spread the word about brain health when Congress appropriated \$1.6 million for our Association and the Centers for Disease Control and Prevention (CDC) to collaborate on educating health professionals and the public on lifestyle strategies to reduce risk of Alzheimer's disease. The appropriation marked the first time the CDC has received funding earmarked for an Alzheimer program.

Diagnosis and Monitoring

Finding preventive strategies will require better ways to detect the earliest Alzheimer brain changes and to gauge treatment effectiveness. The effort to address these issues took a huge leap forward in October when the National Institute on Aging (NIA) announced the Alzheimer's Disease Neuroimaging Initiative (ADNI). This \$60-million, five-year, nationwide study aims to determine whether some combination of brain images and laboratory and psychological tests may offer a better way to identify individuals at high risk for Alzheimer's, track disease progression and monitor treatment response. The Alzheimer's Association will contribute \$1 million to this landmark effort. Michael W. Weiner, M.D., chair of the Alzheimer's Association Neuroimaging Work Group and director of the Magnetic Resonance Unit of the University of California at San Francisco, will serve as principal investigator. Leon J. Thal, M.D., will direct a Coordinating Center for the trial at the University of

California at San Diego, where he chairs the Department of Neurosciences.

The Alzheimer's Association also supports the search for improved diagnosis and monitoring through the activities of its Research Roundtable. This partnership unites Association science staff and advisors with scientists from pharmaceutical companies, universities and regulatory agencies in a collegial effort to identify and surmount common barriers to progress in drug development. Both the Mild Cognitive Impairment (MCI) and Biomarkers Subcommittees of the Research Roundtable held invitation-only meetings to explore conceptual, practical, ethical and regulatory issues involved in detecting and monitoring the earliest cognitive and behavioral changes that may be implicated in Alzheimer's.

Treatment

The year 2004 opened on a hopeful note in the quest for more treatment options with the January availability of the newly approved Alzheimer drug memantine (Namenda). Although memantine is not known to stop the underlying death of nerve cells in the Alzheimer brain, it is the first in a new class of symptomatic drugs and the first approved for individuals in moderate to severe stages of the disease. In February, the Alzheimer's Association partnered with the Alzheimer Research Forum, an online reference resource and virtual community, to host a live, online panel of international experts discussing how availability of memantine might change the dementia treatment landscape.

In another step forward in the treatment of symptoms, the NIA launched a nationwide clinical trial of the herbal supplement huperzine A as a possible treatment for mild to moderate Alzheimer's. Huperzine A has been used for centuries in Chinese traditional medicine, and recent Chinese trials reportedly show some benefit in Alzheimer's disease. The NIA study will be the first U.S. trial comparing a standardized form of huperzine to a placebo. Huperzine is believed to work the same way as cholinesterase inhibitors, medications that have been a mainstay of Alzheimer treatment since the 1993 approval of the first drug in this class.

There is also progress to report in the search for treatments targeting the basic biological missteps that damage the Alzheimer brain. One prime suspect in brain cell malfunction and death is beta-amyloid, a protein fragment that accumulates by stages into the amyloid plaques considered one hallmark of the disease. In August, recruitment opened for a nationwide clinical trial of NC-758 (Alzhemed), an

experimental oral drug that blocks accumulation of beta-amyloid. Elan Pharmaceuticals plc also launched a small trial of its second-generation "Alzheimer vaccine," based on a genetically engineered beta-amyloid antibody. Elan's first vaccine mobilized recipients' own immune systems to produce anti-beta-amyloid antibodies, but that strategy resulted in a risk of brain inflammation.

Beta-amyloid's status as a prime suspect also makes it an attractive target for diagnosis and treatment monitoring. In January, researchers who were funded in part by the Alzheimer's Association published results of their first human trial of Pittsburgh compound B, a substance that appears to latch on to beta-amyloid and "light up" in a brain scan. The Pittsburgh compound's ability to highlight beta-amyloid deposits, if confirmed in further studies, could significantly enhance our understanding of beta-amyloid's role in Alzheimer's disease and normal aging as well as accelerate anti-amyloid drug development.

International Research Conference

Up-to-the-minute data on investigational drugs and advances in brain imaging were among the exciting topics covered at the 9th International Conference on Alzheimer's Disease and Related Disorders, presented by the Alzheimer's Association in Philadelphia in July. A record 4,500 scientists attended 2,000 scientific sessions to hear the latest data on drugs under development; insights into basic Alzheimer biology; new animal models of the disease; emerging evidence on risk factors and preventive strategies; and cross-cultural advances in care and support. Science reported at the conference captured international attention as media coverage generated more than 350 million media impressions worldwide.

Alzheimer's Association Journal

The Alzheimer's Association chose the international research conference as the venue to announce its new journal: *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*.

"Our vision is that *Alzheimer's & Dementia* will be the foremost journal covering the breadth and depth of dementia research and clinical care, from molecular biology through drug and non-drug therapies to prevention and psychosocial aspects of care," noted William H. Thies, Ph.D., Alzheimer's Association Vice President, Medical and Scientific Affairs.

Following a worldwide search, Zaven S. Khachaturian, Ph.D., was selected as the first editor of *Alzheimer's & Dementia*. Khachaturian, an Alzheimer's Association senior science advisor, has served as director of the

Office of Alzheimer's Disease Research at the National Institutes of Health (NIH) and associate director of the NIA's Neuroscience and Neuropsychology of Aging Program.

Quality Care Campaign

In another 2004 milestone, the Alzheimer's Association extended its leadership into the long-term care arena, where there is no model of care for residents with dementia in assisted living or nursing homes. To fill this void, we are launching the Alzheimer's Association Campaign for Quality Residential Care. This initiative unites Association quality care staff, industry and professional groups and consumer advocates in a multi-year effort to establish evidence-based care recommendations. The first three quality standards will focus on food and fluid intake; pain management; and activities and socialization.

Association 2004 Grant Portfolio

Our 2004 \$1 million Pioneer Award in Alzheimer's Disease Research also focuses on important aspects of quality care. The award funds Philip D. Sloane, M.D., M.P.H., to explore poorly understood and rarely studied issues related to improving overall medical care for assisted living residents with dementia. Dr. Sloane's grant is sponsored by **The Judy Fund**, established by the Gelfand family to support the work of the Association, advance research and improve care.

Dr. Sloane's Pioneer Award is one of 71 Alzheimer's Association 2004 grants to projects in virtually every area critical to maintaining our progress. Although all of these projects have the potential to contribute significant insights, they represent only about 10 percent of the record 694 applications for funding. We wish we could have funded closer to the 40 percent our science advisors estimate deserved support. Yet we are heartened that the strong interest in our grant program demonstrates the vitality of the dementia research field and the growing reputation of our Association in advancing the work of talented scientists.

To date, our research grant program has awarded over \$165 million to more than 1,300 projects. Rita Hayworth Gala proceeds have funded nearly 25 percent of that total, contributing \$40 million over the 20 years the galas have been held. Through the ongoing generosity of our donors and the dedication of our staff and internationally recognized volunteer advisors, our Association will continue to work as a science leader, partner and innovator until our vision of a world without Alzheimer's disease becomes a reality. ■



Remembering Judy

by Leslie Gebhart

Today I have a lovely and diverse collection of heart shaped stones.
They come from streams, mountain trails, lakes and unexpected sightings in random locations.
They all remind me of my dear friend, Judy.

AFTER HER DIAGNOSIS AND BEFORE THE FINAL YEARS, we invented new ways to have fun and quality time together. Often she took the lead in spite of the many ways she was being diminished by the ravages of her Alzheimer's disease.

One of the most prolonged and delightful activities we shared was our on-going search for quality heart shaped stones. I recall this as one of the last links we shared as the Judy I'd known and loved slipped away. We would literally spend hours along the lake's edge gently paddling our canoe (I the gallant rower, she the delighted "queen of the boat.") in the shallowest water, singing our songs from yesteryear while turning stones over gently in our fingers to discern whether they'd qualify for our collections. The standards were high.

Judy had high standards both throughout her rich and varied life before the disease began to rob her of it all, and also regarding the heart shaped stones.

It was significant to me to witness her expression of these high standards in our childlike quest for the most perfect heart shapes. "What do you think of this one?" she'd ask even already knowing her answer. We'd debate the issue, turning the pebble or rock this way and that way before she'd give it a toss or slip it into her pocket.

I took a heart shaped stone to the cemetery on the one year



The large blue heart you see mixed among the stones was part of Judy's personal collection. It was a special gift to me after Judy's death.

anniversary of her death. Today my collection is presented among the flowers near the front entrance. I'm enriched with joy by the memory of Judy, our 30 years together and how much she taught me about high standards and love. I'm so grateful for my collection of heart shaped stones. Thank you, Judy! ■

Leslie and Judy met in 1974 as founding members of the Palm Springs Desert Museum Docent Program. Their friendship spanned 30 years and included "girl stuff" such as editing those 'no longer flattering' clothing items from closets, sharing hours on the sidelines of their children's activities, and creating innovative ways to raise funds for non-profit organizations.

Currently, as a life coach, Leslie stands shoulder to shoulder in partnership with her coaching clients as they identify obstacles and create action plans to remove them so their dreams are realized. She uses tools from her formal education as well as those life experiences shared with Judy to create a supportive environment for change. Please contact Leslie at www.lesliegebhart.com or call 760-320-2688 if you would like more information. Coaching makes a difference!

SAVE THE DATE

Wednesday
March 8th

Beverly Hilton Hotel
Beverly Hills, CA

*A Night at
Sardi's*

Honoring
The Judy Fund

THE JUDY FUND

Powerful Partnerships: Philip Sloane, MD, MPH

by Nicole Clifford

DR. PHILIP SLOANE is the 2004 recipient of the Alzheimer's Association's Pioneer Award, the flagship grant within **The Judy Fund** Research Awards and the Association's largest research grant. As he focuses on the quality of care in assisted living facilities, it turns out he is not alone in his passion for improving Alzheimer's care – his enthusiasm runs in the family. He and his wife, Sheryl Zimmerman, PhD, co-direct a program of research at the University of North Carolina at Chapel Hill.



Drs. Sloane and Zimmerman have partnered on Alzheimer's long-term care research for eight years. However, their individual dedication to this area of research began long before their collaboration. Dr. Sloane previously worked as a geriatrician and Dr. Zimmerman as a social worker in long-term care settings. "It became clear to both of us that care of persons with Alzheimer's disease was one of the biggest issues facing persons in long-term care, and as we got more involved in research we maintained this interest," said Sloane.

Both passionate and committed to their research, the Drs. Sloane and Zimmerman are well suited to work together. Not only does their professional collaboration enable them to see each other more often, but they also share the same high standards. Dr. Sloane and



Dr. Zimmerman maintain their professionalism in their research, treating one another like any other colleague. "We're pleased when people who've worked with us for years are surprised to learn we are married," shared Sloane.

Successful collaboration seems to be a theme with Dr. Sloane. One of his career

highlights is partnering with the School of Nursing at Oregon Health and Sciences. After nearly ten years of work, the team developed a training DVD and video that was sent to every nursing home in the country to assist caregivers in bathing Alzheimer's patients. The educational piece has "been taught to and used by thousands of staff and has been incorporated into federal surveyor standards," said Sloane. "Thus, we have had a significant role in helping change attitudes toward bathing to make it a more pleasant experience for everyone."

Thanks to the generous support of **The Judy Fund**, Dr. Sloane has embarked on another exciting partnership to advance Alzheimer's care. He and Dr. Zimmerman are continuing to work together, and kicked off the Pioneer Award project on March 1, 2005. The first component is to better define quality medical care for persons in assisted living. ■

The Judy Fund sponsored the Pioneer Award,
the Alzheimer's Association's largest grant in 2004.

Memories

A Judy Fund Gala

November 19, 2004, Rancho Mirage, CA

by Harriet Baron

The ALZHEIMER'S ASSOCIATION, Coachella Valley Regional Office, proudly hosted the inaugural **Memories A Judy Fund Gala**, on November 19, 2004. An evening of remembrances and celebrations, the gala honored those who have fought and continue to fight their battle with Alzheimer's disease. This was the 6th annual gala, chaired by the founders of the Coachella Valley Regional Office, Pat Kaplan and Edie Keller. The partnership between the Coachella Valley Regional Office and the Gelfand family was

forged out of their alignment behind a common goal, to support the Alzheimer's Association's local and national priorities. Thus they joined resources to bring the Gala to an exciting new level. It was also time to introduce **The Judy Fund** in the place where Judy was most at home and best remembered...Palm Springs.

The Gelfand family lent their considerable support and influence to the gala, appealing to the business, social and philanthropic leaders of the community. As a result, the number of guests soared to over 500 which drove net income to a record breaking \$370,000. The gala also marked the debut of a powerful public service campaign, set against the musical back drop of Barbra Streisand's classic *The Way We Were*.

The evening's Honorary Chairs included Harold Matzner, Barbara Sinatra, Donald and Peggy Cravens (lyricists of *The Way We Were*), and Marilyn and Alan Bergman (composer). Honorary Chairs Congresswoman Mary Bono and Princess Yasmin Aga Khan were also in attendance. The Gelfand Family and the Alzheimer's Association intend for **Memories A Judy Fund Gala** to become a premiere philanthropic event in the Coachella Valley each season.

2005
Memories
A Judy Fund Gala
~
Jackie Lee Houston
Honorary Chair
~
Carol and Glenn Bjorklund
Milton W. Jones

The 2005 **Judy Fund Gala** is scheduled for Friday evening, November 18th at the Rancho Las Palmas Resort & Spa and promises to be as exciting and even more successful than last year. Jackie Lee Houston is the evening's Honorary Chair, and Edie Keller and Pat Kaplan serve as Co-Chair of this year's event. Milt Jones, President of The Jones Agency and Desert Publications, Inc., will be honored with the 2005 Judy Gelfand Community Service Award for his leadership in increasing awareness of Alzheimer's and local programs and services available to the community. Carol and Glenn Bjorklund will receive The Maureen Reagan Caregiver Award for not only providing care for Carol's mother for ten years, but also for their dedication to developing programs and activities for Alzheimer's patients at her mother's care facility. For more information please contact the Coachella Valley Regional Office directly at 760-328-6767. ■



Marshall Gelfand, Elizabeth Gelfand Stearns, Edie Keller, Pat Kaplan and Michael V. Smith



Neil Diamond, Berry Gordy, Jr., Princess Yasmin Aga Khan and Jack Jones



Dr. Jeffrey Cummings, Stuart Roth, Princess Yasmin Aga Khan, Jerry Stone, Peter Braun

Memories, Like the corners of my mind Misty water-colored memories Of the way we were

Scattered pictures, Of the smiles

For the way we

every line? If we had the chance

may be beautiful and yet What's

We will remember

Memories, Like the corners of my mind

Scattered pictures, Of the smiles

For the way we

every line? If we had the chance

may be beautiful and yet What's

We will remember Whenever we remember... The way we were... The way we were...

The Judy Fund

Care and Cure with the Alzheimer's Association

CALENDAR OF EVENTS

October '05

**22 Los Angeles
Memory Walk**

Hollywood Park Racetrack
Inglewood, CA
323-930-6228

November '05

18 Memories A Judy Fund Gala

Rancho Mirage, CA
760-328-6767

February '06

**4 Coachella Valley
Memory Walk**

Rancho Mirage, CA
760-328-6767

March '06

**8 A Night At Sardi's
Honoring The Judy Fund**

Beverly Hills, CA
323-930-6239

The Judy Fund supports the Alzheimer's Association
225 North Michigan Avenue, 17th Floor, Chicago, Illinois 60601 Telephone 312-335-5739
www.alz.org