

VISION

CREATING A WORLD WITHOUT ALS



VOLUME 2 FALL 2009



Howard Weese was asked by the Colorado Rockies to read Lou Gehrig's speech

on July 4. Weese, diagnosed with ALS in April, has been associated with the Rockies from the beginning, serving on the committee that worked to bring the team to Denver. From 1995 until this year, Weese was the Left Field Club Level Supervisor; in addition, he supervised security, media relations and the dining facilities during the Rockies' spring training in Tucson, Ariz. "It was an honor to read the speech, and I'm thankful to have worked at the ballpark," said the ever cheerful Weese adding his motto, "life is utterly fantastic."



Los Angeles Angels third baseman, Chone Figgins, with the 4ALS logo on his jersey.

4ALS Baseball Event Remembering Famous Lou Gehrig Speech is a Big Hit

by Gary Wosk

It was the bottom of the ninth inning, bases loaded, two out and The ALS Association stepped up to the plate for Major League Baseball's "4ALS Awareness" initiative last July. The ALS Association quickly swung into action and staged an unprecedented rally that helped elevate awareness about Lou Gehrig's Disease to perhaps its highest level ever and raised funds for its global research program.

Also adopted by Minor League Baseball, "4ALS" commemorated the 70th anniversary of Lou Gehrig's

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Antisense Clinical Trial Announced

A new experimental therapy using an approach known as antisense, in which a drug is designed to shut down the RNA (Ribonucleic acid) that is responsible for the production of disease-causing proteins, is being prepared for a clinical trial in people with a familial form of ALS later this year. The clinical trial follows research funded by The ALS Association through TREAT ALS® (Translational Research Advancing Therapy for ALS), our research pipeline that funds and facilitates the development of treatments for ALS based on important laboratory findings.

The research that resulted in the identification of this antisense drug was first funded by The ALS Association in 2003, and has been developed for the clinic through an academic/industry partnership. ALS Association-funded researchers Drs. Don Cleveland, Richard Smith and Timothy Miller, in partnership with Isis Pharmaceuticals in Carlsbad, Calif., initiated experiments in a rat model of ALS to determine whether reducing the amount of SOD1 protein may be beneficial in treating the disease.

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Tim and Katie Nicholson with their parents Nick, who has ALS, and Jo Nicholson with New York Yankees shortstop Derek Jeter at Yankee Stadium.

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Lou Gehrig Speech Continued from page 1

famous “Luckiest Man” speech at MLB and Minor League Baseball stadiums on July 4.

People living with ALS and their families have more hope that new treatments and a cure will be discovered as a result of the initiative and the awareness it has raised.

“This was one of the highest profile events in the history of fighting Lou Gehrig’s Disease,” said Jane H. Gilbert, president and CEO of The ALS Association. “The close to two million fans who visited ballparks during ‘4ALS’ and the millions more who watched on television or listened on radio now know much more about this terrible disease and why their support is needed,” Gilbert continued.

Even now, excitement surrounding “4ALS” and the groundswell of support for making this an annual tradition continues to grow.

“I cannot tell you the satisfaction it’s given me and the clubs to participate in something like this. It is so worthwhile,” said MLB Commissioner Bud Selig.

The Association’s national network of chapters raised money for services and programs through The Association’s “Covering All the Bases Hitting

Challenge,” where fans pledged a dollar amount for each hit their favorite team made. “We were extremely pleased that the total hits of nearly half of our domestic clubs on July 4 resulted in monies being raised for ALS,” said Minor League Baseball President Pat O’Conner.

Highlights from “4ALS” included the introduction of patients and spouses; live readings of Gehrig’s speech by patients, celebrities and players; the playing of public service announcements by former MLB players Curt Schilling and Nolan Ryan; and auctions.

Players and coaches wore the “4ALS” patch on their chest, and the “4ALS” logo appeared on stadium scoreboards, signage and on first base. In addition, teams donated suites to chapters to host patients and families.

“On July 4th, more people received an introduction to ALS, what it is, what it does, and what it means, than on any day in the history of mankind,” said Schilling, who has raised more than \$10 million through his “Curt’s Pitch for ALS®” program and other events for The Association.

At Yankee Stadium, Yankees shortstop Derek Jeter and several teammates read the speech. “It was very emotional for both the players and the fans, and it truly was a goose-bumps moment,” said ALS Association Greater New York Chapter president and CEO Dorine Gordon.

Larry Pouncey, who has ALS, participated in a pre-game ceremony with his wife Linda at Angels Stadium of Anaheim. “It’s actually overwhelming,” he said. “I find the outpouring of love humbling, and it makes me proud.”

Just before his name was announced to the crowd, he spoke about his wife. “She has gone through a lot seeing me go through this, and it means a lot to her to see MLB doing something for ALS awareness,” Pouncey said.

MLB’s Web site promoted the initiative and featured a blog, where Jim Huff of Poplar Bluff, Mo. wrote “Dad is still fighting the good fight, and it is awesome to know that so many people are standing behind the men and women with ALS. I am sure when he saw the evening news a huge smile came to his face.”

Twenty-Five Years of Hope

A message from Jane Gilbert, President and CEO



Jane H. Gilbert

January 2010 marks the beginning of The ALS Association’s 25th year in the fight against Lou Gehrig’s Disease. Our vision to create a world without ALS has provided inspiration for our efforts every single day of this last quarter century.

In the few months that I’ve had the privilege to serve as President and CEO, I’ve learned that The ALS Association means many things to many people. It is the global research laboratory where scientists search for treatments and a cure. It is compassionate care that embraces and empowers the entire family through a network of chapters and certified treatment centers. It is a strong voice in government for those who have lost their voice. And, it is the

premier source for knowledge and information about this devastating disease.

Moreover, to everyone in the ALS community, The ALS Association means a reason for hope. With advances in science and technology in recent years and the continued help of donors like you, there is more reason than ever to believe that effective treatments may soon be within our grasp.

Our pledge is to leave no stone unturned in the quest to put an end to this disease, once and for all. Working together, we will relegate Lou Gehrig’s Disease to its rightful place in the history books. Thank you for being a part of our quest.

Generosity Gene Handed Down from Father to Daughter

by Robert Ward

Louis B. Neumiller was CEO of Caterpillar in Peoria, Ill. from 1941 to 1954. His contributions to Caterpillar, to Peoria and to American business extended through much of the early 20th century. He led the transformation of Caterpillar—with whom he started as a clerk in 1915—into the global company it is today. He founded Junior Achievement in Central Illinois. He believed that in any situation the most important thing was the people involved. When he was diagnosed with ALS in 1987, his wife, three daughters, other family and friends supported him. He died in 1989.

Anamarie Neumiller says: “My father was a kind and generous man who wanted to help others. He was blessed with excellent health for more than 80 years, but one day he noticed his arms were getting weaker. Small tasks using his hands became more difficult. He had ALS. His optimism, his faith and the people who loved him made his days bearable.”

Anamarie has included The ALS Association in her estate plan and has been a volunteer and a contributor to the Walk to Defeat ALS in Peoria. So when she was invited to consider a proposal to support The ALS Association St. Louis Regional Chapter and through the chapter, the research program of The Association, she readily agreed.

“The ALS Association St. Louis Regional Chapter is trying hard to meet the needs of patients and the family members to cope with tough day-to-day issues of their disease. I am happy to donate funds for the Louis B. Neumiller Research and Chapter Support Fund, and I continue to hope that the research professionals make strides of their own to find a cure for ALS!” Anamarie says.

Anamarie chose to focus her research support on efforts to find biomarkers for earlier diagnosis and improved clinical trials for ALS. A strong influence for her was an ALS Association Research Update detailing the work of Merit Cudkowicz, M.D. of Massachusetts General Hospital, recipient of the 2009 Sheila Essey Award for ALS Research. Anamarie made her gift in recognition of the contributions of

women leaders in ALS research as exemplified by the work of Dr. Cudkowicz and of Lucie Bruijn, Ph.D., Senior Vice President, Research and Development for The ALS Association. Says Dr. Bruijn: “Biomarker research is extremely important, especially now as we place increased emphasis on accelerated efforts to develop therapies through our TREAT ALS program. We are grateful for this wonderful gift.”

And Jane Gilbert, President and CEO of The ALS Association, expresses the sentiment of the entire organization: “We are pleased to establish the Louis Neumiller Fund in memory of a great leader and a wonderful man, and we thank Anamarie Neumiller for creating the opportunity to do so.”

To learn more about how you can pay tribute to loved ones and support The ALS Association, please contact us at (888) 949-2577.



Louis B. Neumiller with his dog, Geordie.

Corporations Walk the Walk and Talk the Talk for ALS Cure

by Gary Wosk

More and more corporations are recognizing the value of getting involved with The ALS Association's Walk to Defeat ALS®. It's a great way to support the community, it fosters employee teamwork, and it's a fun and rewarding way to help find treatments and a cure for people fighting Lou Gehrig's Disease.

“We have 60 people in our office and we have 42 walking... we have another 8 to 10 volunteering, so that is about 90 percent of the people participating. We really couldn't think of a better way to spend a Saturday,” said Brian Higgins, senior customer manager for General Mills, about the Walk.

Corporations are helping the event to expand and make even more of an impact as it nears its 10th anniversary.

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Veteran's Benefits Extended to People with ALS and Surviving Family Members

by Janet Young

The ALS Association secured a tremendous victory for our nation's military veterans as the Department of Veterans Affairs issued historic regulations that establish ALS as a “service connected” disease. This means that veterans with ALS are now eligible to receive comprehensive benefits, including monthly disability compensation, adaptive housing grants, automobile grants, adaptive equipment, and aid and attendance allowance, as well as full health care.

Importantly, these benefits are available regardless of where or when veterans served in the U.S. military and regardless of whether they were diagnosed with ALS while in the military or decades after discharge from the service. Benefits also are available to dependents and surviving family members who have lost a loved one to ALS even if the veteran passed away years or

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ALS Association®

Allen L. Finkelstein_Chair, National Board of Trustees

Jane H. Gilbert_President and CEO

Jeff Snyder_Vice President, Communications

Greg Cash_Director, Communications/Editor

20 Years



4. *“Much has changed since my husband’s death from ALS in 1987. As a charter member of the Research Council, I have faith and belief that the funding of the many research projects will ultimately make the desired progress we all seek.”—Helen Weber*

faith

Steadfast Friends Daring to Dream

Twenty years ago, a small group of thoughtful committed people made a decision to dedicate part of their financial resources to the fight against ALS.

Daring to dream of a cure for the disease, their goal was to lead the way for advances in research by making yearly gifts of \$1,000 or more in support of The ALS Association’s research program. The faith of these Research Council charter members in a future without Lou Gehrig’s Disease has not wavered. Their foresight and generosity continues today, 20 years later.



Monica and Charles Burkett

“My father died as a result of ALS at the all too young age of 55. There are many good causes to support, but I decided to become a charter member of the Research Council because I saw firsthand the effects of this

disease and feel The ALS Association has a very organized plan to tackle this difficult and complex disease. I am kept informed of ongoing research and see promising results each year.”—Charles Burkett, M.D.



“I’m happy to support The ALS Association’s research program through membership in the Research Council.

We look forward to the day when treatment for this terrible disease—which claimed the life of my husband—is discovered.”
—Jean Kamm

The Future is Hopeful

“From faith to hope,” is how Robert V. Abendroth, Chairman of The ALS Association’s Research Committee and Founder of the Research Council, recently



Robert V. Abendroth

characterized progress in ALS research in the past 20 years.

More breakthroughs in understanding the disease mechanisms of ALS, and in uncovering new insight into potential treatment, have been achieved in the last decade than at any time since ALS was first described more than a century ago. The ALS Association is currently funding 80 research studies in leading laboratories around the world.

Through TREAT ALS, The Association’s pioneering research program to bridge the gap between laboratory discoveries and treatments for ALS, The Association hopes to develop one or two drugs which can be ready for large-scale FDA-approved clinical trials within five years.

“Through innovation, partnerships and a global research commitment, investigators will find the answers to the disease. The Association’s research program is important not only for funding the most promising studies, but acting as a catalyst for new ideas and opportunities,” commented Dr. Lucie Bruijn, Senior Vice President of Research and Development. “Through your generous support, we will make a difference for people living with ALS.”

1985 The ALS Association is formed from the merger of two ALS organizations.

1989 Research Council established by Robert V. Abendroth, Esq., Chair, Research Committee.

The ALS Association funds search for a common genetic link to ALS.

1993 First ALS gene, SOD1, discovered. Linked to 20% of familial ALS cases.

1994 Development of first-ever animal model of ALS, using SOD1 gene. Animals exhibit ALS-like symptoms and provide researchers vital information about the disease.

1995 FDA approves riluzole, first drug ever approved for treatment of ALS.

2001 ALS2 gene discovered, linked to juvenile ALS.

2002 Department of Defense approves funding for ALS-specific research. The ALS Association holds scientific workshop on “Environmental Factors and Genetic Susceptibility.”

2003 Gu... deployed ALS at tv... The ALS... U.S. Depa... all veteran

of Dedication to ALS Research

Help Lead the Way to a Cure for ALS: Become a Member of the Research Council

This is a pivotal time. Great progress has been made. The ALS Association is determined to succeed in transforming ALS from a terminal illness into a treatable illness, but we need your help.

When you make an annual gift of \$1,000 or more, in support of ALS research, we will be honored to welcome you as a member of the Research Council. Membership gifts may be spread throughout the year through quarterly payments. You may also become a member through a gift of stock or other asset.

Benefits to Membership:

- Research Council members are invited twice a year to participate in a teleconference where they hear from Dr. Bruijn, and view a presentation in which she explains groundbreaking discoveries, such as the ALS6 gene, discovered earlier this year. Members are invited to participate in a question and discussion session following Dr. Bruijn's presentation.
- Members also receive *Research Update*, a bi-monthly publication providing up-to-date information about ALS research breakthroughs.

The ALS Association would be delighted to welcome you as a member of the Research Council. You may enclose your membership gift in the envelope provided. Or, to find out more about how you can help lead the way to a cure for ALS, please contact Karen Starleaf, toll-free at (888) 949-2577, extension 211, or through an email to kstarleaf@alsa-national.org. You can also learn more about the Research Council by visiting The Association's Web site at www.alsa.org/researchcouncil.

We are proud to recognize these steadfast friends, whose exemplary philanthropic spirit has helped to build the most comprehensive research program ever organized to find a cure for Lou Gehrig's Disease.

- Charles M. and Monica A. Burkett
- Margaret A. Carver
- Michal Freedman
- Dr. John F.* and Linda Jenkins
- Jean Kamm
- Stanley M.* and Laurene V. Knedlik
- Jean McEvoy O'Brien
- Bernard H. Paiewonsky
- David A. Ralston
- Lawrence and Madelon Rand
- William A. Rogers
- Meta Calise Sanborn
- Patricia N. Stiede
- Helen F. Weber
- Richard F.* and Mary J. Wiggins

* Deceased

"As a physician, John had seen the effects of ALS and knew the disease caused tremendous suffering. He remained passionate about supporting ALS research until his death in 2008."

—Linda Jenkins

hope

ALS Research Dollars

Pay Dividends by Lucie Bruijn, Ph.D.

With the support of your generous donations, several important research findings have been made this year that pave the way for new directions in the laboratory and new treatments in the clinic.



Dr. Lucie Bruijn

Following the discovery of new genes linked to some cases of inherited ALS reported earlier this year, scientists are developing new models to test therapies for the disease. While the recent gene findings are in early stages of the discovery process, the pivotal discovery of mutations in a gene superoxide dismutase 1 (SOD1) funded by The Association has led to the first antisense clinical trial (see cover article) for inherited ALS with an approach to lower production of the abnormal, unwanted proteins.

The ALS Association's TREAT ALS (Translation Research Advancing Therapies for ALS) pipeline ensures that important laboratory findings receive the financial and scientific support to take these discoveries from the bench to the bedside. Recently, the Food and Drug Administration approved the first stem cell trial for ALS. Without your support, we would not have been able to fund Dr. Nick Boulis's studies to develop the surgical procedures for the clinical trial. To learn more about this study and how you can support our global research efforts please visit our Web site <http://www.alsa.org/neuralstem> or call (888) 949-2577.

Thank you for your support. Together, we can make a difference in the fight against Lou Gehrig's Disease by finding therapies and ultimately a cure.

Lucie Bruijn is The ALS Association's vice president, Research and Development.

2004 War study shows that veterans with ALS have a 50% higher risk of death than those without ALS. The Department of Veterans Affairs is enrolling veterans with ALS into a registry.

2004 Study funded by The ALS Association to find biomarkers in cerebrospinal fluid and blood.

2005 Potential biomarkers for ALS identified. The ALS Association launches TREAT ALS (Translational Research Advancing Therapies for ALS) to accelerate clinical trials in ALS.

2006 First TREAT ALS clinical trials begin.

2007 ALS U.S. registry efforts gaining ground in Congress. Engineered stem cells discovered to help motor neurons survive in SOD1 rats.

2008 Motor neurons created from skin cells from people with ALS. Recognized as "No. 1 Medical Breakthrough in 2008," by Time Magazine. Mutations in a gene called TDP-43 linked to familial and sporadic ALS. The ALS Association invests in a major clinical trial to determine if lithium can slow disease progression in patients in the very early stages of ALS.

2009 New gene, ALS6 (FUS), discovered. Linked to 5% of familial ALS cases. Protective gene discovered that may help researchers understand factors that improve survival in people who have ALS. 20-year anniversary of the Research Council. Researchers discover that ALS progresses at a more rapid pace in patients whose gene mutations cause faster clumping of the SOD1 protein. Clinical trial planned to slow production of mutant SOD1 in people with ALS who have this gene.

Corporations for ALS Cure

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"The corporations that embrace the Walk have helped elevate it to one of the premier fundraising events in this country, and they can feel good about helping lead the fight against ALS," said Jane H. Gilbert, president and CEO of The Association.

The Walk to Defeat ALS is expected to draw approximately 140,000 annual walkers to Walks in 150 cities. This year, the goal is to raise \$18 million. When the Walk began in 2000, the goal was to raise between \$50,000 and \$100,000.

"By 2012, we expect funds generated by corporate Walk teams to represent about 35 percent of total Walk revenue, said Marilyn Simon-Gersuk, ALS Association vice president of development."

The involvement of such corporations as Booze Allen Hamilton, which helped The Association develop the Walk program, PepsiCo, Walmart, Quicken, Blue Cross/Blue Shield, Permobil and many others has immensely boosted the event's revenue from \$9.8 million to \$16.4 million in just three years.

"ALS is a disease that is very crippling," said Terry Orman, business development manager for Frito-Lay and PepsiCo. "Between PepsiCo, Frito-Lay and QTG (Quaker, Tropicana, Gatorade), we put together a (Walk team) plan that we thought might elevate the support we could get for ALS."

The ALS Association and corporations have benefitted from the partnership and as a result are accomplishing many of their goals.

"More people are turning out to Walk and raising money to fund ALS Association programs that support research and services for people with Lou Gehrig's Disease and their families," said Ashton Chase, senior director for National Signature Events at The Association. "Corporations have discovered that participating in the Walk demonstrates good corporate citizenship, and their employees feel good about supporting a great cause."

Corporate involvement in the fight to defeat ALS is of vital importance to patients and caregivers.

"It means so much to us when VIPs and employees from the business community take time out from their busy schedules to support our cause," said Charles Fritz of Prairie Village, Kansas whose wife Marlene has ALS.

The uplifting spirit of the Walk has become attractive to corporations and employees because they are giving back to the communities where they live and work while having fun and teaming with fellow employees.

"This experience has been extremely positive for us," said Don Frieson, senior vice president of Walmart. "We have a huge Walk team. Our associates have been incredibly supportive. I would encourage any company that really wants to rally around a cause, around people, that the Walk is it."

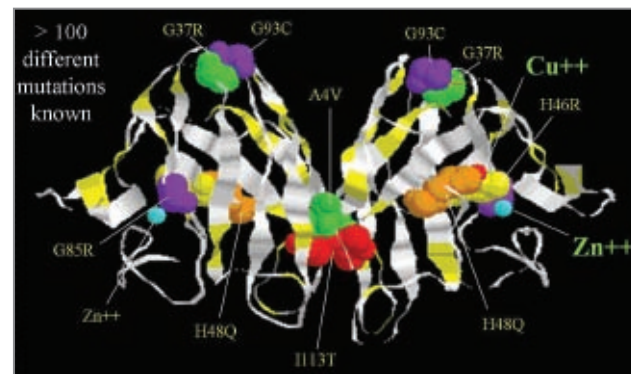
Antisense Announced

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Initial research in rat ALS disease models demonstrated that the antisense drug inhibited the mutant SOD1 protein, resulting in prolonged life of the rats. Time of treatment for the rats was near onset of symptoms, reflecting the scenario for actual patients who often have definite and even advanced signs of motor neuron loss by the time of ALS diagnosis. Researchers hope that this therapeutic approach will provide a similar therapeutic benefit in people with familial ALS due to mutations in the SOD1 protein. The antisense approach could also prove valuable in treating other neurological disorders, such as Huntington's disease.

Together with the biotech company Isis, led by Drs. Frank Bennett, Timothy Miller, Merit Cudkowicz and Richard Smith, the team has conducted the necessary research to submit an Investigational New Drug Application with the Food and Drug Administration (FDA) to test this novel approach in people with ALS. The application was recently submitted to the FDA. The ALS Association will provide funding for the clinical trial.

"This achievement, and the process of taking an idea from the laboratory to the clinic, underscores the importance of The ALS Association's TREAT ALS pipeline and the financial support provided to the investigators," commented Senior Vice President, Research and Development Lucie Bruijn, Ph.D. "The development of new treatments is an extremely challenging and costly process. It is



SOD1 gene

only through the support of our generous donors that this type of research is made possible."

People interested in learning more about the clinical study should contact the Massachusetts General Hospital Neurology Clinical Trial Unit at (877) 458-0631 or by email at ghneuroclinicaltrialsunit@partners.org

The ALS Association's research program brings together the best scientific minds from the research and biotech communities to focus on finding the cause of ALS, developing effective treatments, and ultimately, a cure. We are currently funding more than 80 studies around the world, partnering with the scientific and biotech communities. To learn more about how you can support The ALS Association's premier ALS research program and studies such as the antisense clinical trial, visit our Web site at www.alsa.org.

Eagle Scouts Tribute to Grandfather Supports The ALS Association by Janet Young



Paul Carver, Sr.

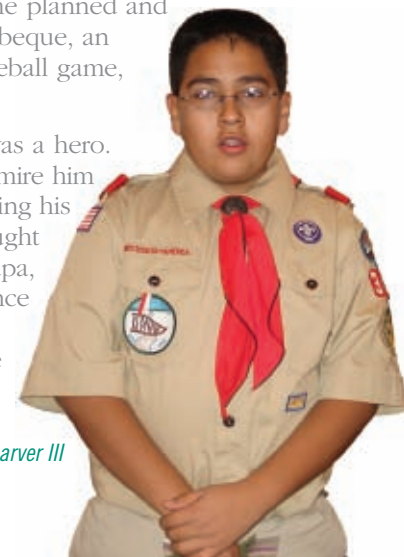
For 14-year-old Paul Carver, III, a Boy Scout project was an opportunity to pay tribute to his grandfather, Paul Carver, Sr., who lost his life to ALS four years ago, and raise nearly \$1,700 to support The ALS Association's Utah Chapter.

To earn the Eagle Scout designation within Boy Scouts, Paul had to plan and develop a service project that could benefit his local community. He chose to organize an ALS awareness and fundraising project. To launch his project, Paul made a presentation to his church group about ALS and the impact it had on his life as he watched his grandfather battle the disease. Next, as part of The ALS Association's Advocacy efforts, Paul collected close to

80 letters for the Chapter's Advocacy Day Letter Writing Campaign. Finally, he planned and organized a community barbecue, an exhibition Little League baseball game, and a silent auction.

"In my eyes, my grandpa was a hero. My hero," Paul shared. "I admire him for being strong and not losing his faith and his spirit as he fought ALS. By honoring my grandpa, I hope I can make a difference for those who are suffering from ALS and for all people whose lives have been touched by this disease."

Paul Carver III



A Legacy of Hope

Navy Captain Robin Quigley finished off her distinguished career in San Diego, Calif., as the commanding officer of one of the Navy's largest technical training activities. She assumed command of the 4500-man Service Schools Command in April 1973, and at her retirement ceremony in September 1974, she remarked that it was her privilege to leave a legacy to the Navy of "the finest group of committed professionals who do not operate this Navy—they perpetuate it."

That professional legacy transitioned later into a personal long-term covenant to care for her aging mother. It was during this time that, although her family and friends had never been touched by ALS, she was inspired by Joe Martin, a community leader in nearby Charlotte, N.C., who had chosen to take his ALS diagnosis public. When asked how he managed to cope with the challenge, he replied simply: "you do what you've been given to do." As Robin notes, "hearing" this sophisticated, worldly man describe how he dealt with the indescribable—ALS—in terms as familiar, as unassuming as the sun rising every morning, resonated deeply. It was a compelling call to make his mantra an integral part of her life, and it began her commitment to a decade of annual gifts to The ALS Association.

Now, at 80, Robin has recently named The ALS Association as a beneficiary in her will. She has joined the ranks of a growing number of friends who have made us part of their family by including The Association in their estate plan.

In recognition of her generosity, Robin has been welcomed as a member of The Legacy Society. This generous group of donors provides vital support for our global research efforts to find a cure for ALS while helping those currently battling this disease.

Please join Robin in celebrating the life of someone special with a gift in your will or trust. To help you meet your financial needs and provide for your family, as well as organizations you care most about, like The ALS Association, we are pleased to offer you a *Personal Estate Planning Guide*. This valuable tool includes a Lesson Book, Record Book and CD.

To request your free copy of the *Personal Estate Planning Guide*, please check the box on the enclosed envelope and return it to us.

If you have any questions or would like to discuss this opportunity further, please contact David Moses, Director of Gift Planning, toll-free at (888) 949-2577, ext. 212 or dmoses@alsa-national.org. All inquiries are strictly confidential.



Robin Quigley

...although her family and friends had never been touched by ALS, she was inspired by Joe Martin...who had chosen to take his ALS diagnosis public.

Veteran's Benefits

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decades before implementation of the new regulation.

Joan Kloehn learned about the benefits through a friend. She lost her husband, Marvin, to ALS in January 2009. Marvin had served in the United States Army in the 1950s, stationed at Fort Bliss in Texas. She applied for benefits in March 2009 and started receiving benefit checks in April. "I've never seen anything move that quickly," Joan said.

"Veterans living with ALS now have one less hurdle to face on an already difficult road," said Steve Gibson, The Association's vice president of Government Relations and Public Affairs. "Our heroes who have served in the military and those serving today can now be reassured that our government will fight for them just as they fought for us."

To learn more about the benefits available to military veterans and their families, or to find out how you can apply for benefits, please visit our Web site at www.alsa.org/policy/veterans.cfm.

Making a Difference by the Numbers

The ALS Association provides people with ALS and their families an active and strong voice in Washington, D.C., and state capitals across the country. Our efforts are making a difference and are helping to create the roadmap that will lead to a treatment and cure for Lou Gehrig's Disease. The numbers below demonstrate the power of our advocacy.

100,000

The dollar amount in disability compensation that military veterans with ALS may receive each year thanks to new regulations The ALS Association helped to establish at the Department of Veterans Affairs.

O Number of diseases besides ALS for which Congress has waived the 24 month Medicare waiting period. The ALS Association worked with Congress to waive the waiting period for ALS in 2001, enabling people with ALS to access vital Medicare benefits much sooner.

2008

Year The ALS Association helped to enact the ALS Registry Act and establish a national ALS patient registry, which may become the single largest ALS research program ever created.

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Run to Defeat ALS Pin-up Program Off to a Great Start

The Run to Defeat ALS pin-up program, created and developed collaboratively by The ALS Association and Maritz Corporation, is designed to educate the public about Lou Gehrig's Disease and raise funds to support research, patient services programs, public education and advocacy efforts.

Retail store cashiers sell paper sneaker pin-ups for \$1 to customers at the point of sale. The most successful pin-up partners are companies with multiple, high-traffic retail outlets, such as grocery chains, drug stores and clothing retailers. The more people that visit the participating stores, the better The Association is at meeting our goals of creating awareness and raising funds.

In its first year, the pin-up program was initiated at four different retail outlets, generating significant revenue and ALS awareness for participating chapters. The continued success of the Run to Defeat ALS pin-up program will bring The Association closer to creating a world without ALS. For information about how your business can participate, send an e-mail to: pinups@alsa-national.org.

