VISION
CREATING A WORLD WITHOUT ALS

ALS Association
Fighting Lou Gehrig's Disease

VOLUME 1 SPRING 2009

R521H FUS image courtesy of Dr. Tibor Hortobágyi, King's College London.

Fused in sarcoma gene provides one more piece of the ALS puzzle and new hope for finding the causes, treatments and a cure.

New Gene Discovery Promises Insights into Causes, Treatments for ALS

by Richard Robinson

In a major breakthrough for ALS research, scientists have discovered a new gene that, when mutated, can cause ALS.

This is the second ALS gene discovered in the past 12 months and brings the total number of known disease-causing genes to three.

"This is a momentous discovery in furthering our understanding of ALS," said Lucie Bruijn, Ph.D., senior vice president of research and development at The ALS Association. "A new gene provides a new piece of the puzzle we can use to shed light on why ALS develops and where to focus our efforts on creating new treatments and finding a cure."

The new gene is called ALS6 or FUS (for "fused in sarcoma"), and accounts for about 5% of inherited

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Major and Minor League Baseball Swinging for the Fences in Knocking out ALS

by Gary Wosk

The ALS Association has joined Major League Baseball and Minor League Baseball in the new "4♦ALS Awareness" initiative that commemorates Lou Gehrig's dramatic 1939 farewell speech on July 4th this year in baseball stadiums across the nation.

Fans everywhere will be cheering for people with ALS and their families, elevating awareness of the disease to an unparalleled level and raising funds for research.

"The courage of Lou Gehrig embodies each and every service and program we offer to the brave men and women living with ALS," said The Association's National Board of Trustees Chairman Allen L. Finkelstein. "It is his spirit that inspires us on a daily basis to do all we can to discover new treatments and a cure."

Three other ALS organizations, ALS TDI, MDA/Augie's Quest and Project A.L.S., also are participating in the

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New Gene Discovery

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cases of ALS. Inherited cases together account for about 10% of all ALS. Scientists will use the new gene discovery to create cell and animal models, to examine in detail how the mutation operates and how it causes ALS.

Normally, the FUS gene carries out multiple functions within the motor neuron (motor neurons are the type of nerve cell affected in ALS). It is not yet known how mutations in the gene cause the disease, and this will be a major focus of future research. Importantly, the FUS gene is involved in some of the same processes as the other recently discovered ALS gene, called TDP-43.

"The fact that these two genes help perform the same function suggests that problems in this function may be critical in the development of ALS," Dr. Bruijn said. "More research into exactly how these two genes work could ultimately lead to new treatments that are effective in slowing or stopping the progression of ALS and extending the lives of people with the disease."

The gene was discovered by an international team, including ALS Association-funded researchers Caroline Vance, Ph.D., and Christopher Shaw, M.D., of King's College in London, as well as Tom Kwiatkowski, M.D., Ph.D., at Massachusetts General Hospital, and Robert Brown, M.D., of the University of Massachusetts School of Medicine. The results were reported in the February 27 issue of the prestigious journal *Science*.

The project was supported by a consortium of leading ALS researchers from around the world, formed as part of The Association's Gene Identification Project. Their success reflects an unprecedented effort to accelerate the search for genetic mutations linked to all forms of ALS. Dr. Brown noted, "The ALS Association has been an all-important partner in this search. This discovery should lead to new cell and animal models of ALS, which will accelerate drug development."

A Healing Journey

by Katie Sweeney

Mariah Fenton Gladis with sons Luke and Cole.

Ron Gladis

In the summer of 1981, Mariah Fenton had everything to live for. Just 33, she was athletic and active, had her own psychotherapy practice and was dating a wonderful man, Ron Gladis. The last thing she was expecting was an ALS diagnosis. Even worse, doctors at the time gave her only a 10 percent chance of living two years.

"It was terrifying and shocking," she recalls. "As far as I knew, I was healthy. Luckily, Ron was very supportive and adamantly optimistic."

In fact, three months later, the two were married, and Mariah soon became pregnant with their first child, Luke. Later, she gave birth to a second son, Cole. Today, 27 years after her diagnosis, both sons are grown—and Mariah Fenton Gladis has more than proved those first doctors wrong.

She continues to see a full caseload of clients at the Pennsylvania Gestalt Center she founded in 1976, has her own foundation, has received numerous professional awards and recently wrote and published a book, *Tales of a Wounded Healer: Creating Exact Moments of Healing*.

One way she's coped with the constant challenges of ALS is by focusing on helping others. In her work, she found a new sense of urgency to empower her patients to change and move beyond the pain in their lives. While writing *Tales of a Wounded Healer*, she gradually became more courageous about revealing deeper parts of herself in the book. She's now planning to write a second book.

"I love what I do, and it gives meaning to my life," she says. "It also keeps me constantly focused on healing, so I'm in that healing energy hour after hour, day after day."

Her advice to others battling ALS? Maximize your overall health; love and forgive everyone, especially yourself; turn your anger into determination; and make peace with the possibility of death—while doing everything possible to stay alive and vital. And most importantly, reach toward people and things that offer hope.

Mariah's beacon of hope has been her husband, Ron, who spends much of his time caring for Mariah.

"It used to be hard for me to hear Mariah say she is a better person because of ALS," Ron said. "But I understand it now. We manage with grace, hope and gratitude because that's the learning that comes out of it."

Your support helps The ALS Association provide services to people with ALS and their families, and supports The Association's global research effort to find treatments and a cure for Lou Gehrig's Disease.

ALS Association Cure ALS Campaign with Angela Lansbury Wins Platinum

ALS Association's Dr. Lucie Bruijn and Angela Lansbury visit with Today Show's Al Roker.

The Cure ALS Campaign, introduced by Lansbury on NBC's "Today" show in the spring of 2008, is proving to be very successful. And now, the campaign as well as the TV public service announcement have both been recognized by the Association of Marketing and Communications Professionals with the highest level, Platinum MarCom Awards.

"Angela Lansbury put her heart and soul into this work," said Jeff Snyder, vice president of communications for The ALS Association. "After losing her sister, Isolde, to Lou Gehrig's Disease, Angela has joined The Association in our quest to 'create a world without ALS,' and we are proud that the Cure ALS Campaign and the PSA received MarCom Awards."

From the get-go, the campaign, which also received a major boost from the Associated Press and "CBS' Weekend Roundup with Dan Raviv," has been a hit. It is estimated that the AP story and companion video, distributed to 1,700 newspapers in the U.S. and 6,000 broadcast outlets, alone may have been read and heard by more than half of the world's population.

The Los Angeles Times, International Herald Tribune, Boston Globe, San Francisco Chronicle Examiner and Orlando Sentinel were among the newspapers that published the AP story. Even the supermarket tabloid Globe published a sensitive, straightforward story.

Lansbury's powerful message has reached film-goers, primarily in the eastern United States, as a result of the efforts of Clarke Mazza, the president and CEO of Pot O'Gold Productions, Inc. and the Florida Chapter of The Association. The PSA was shown 175,000 times in independent theaters. That's not all. Flyers have been viewing the PSA at many airports that carry CNN's Airport Network.

The PSA has also found a home on national TV network affiliates and had reached an audience of nearly 92.2 million; whereas the radio PSA had carved out its own niche, reaching an audience of nearly 17.1 million people, both as of February 2009.

The availability of Lansbury's PSA on MySpace, Facebook and YouTube also has been a major contributing factor to success of The Association's debut on these social networking web sites.

And, don't be surprised to see Lansbury in the waiting room of the doctor. She is featured in the September/October issue of *WebMD the Magazine*.

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*

Cassandra's Sweet 16 – A Gift to The ALS Association

by Karen Starleaf

For Cassandra Koegel, her 16th birthday was an opportunity to bring her wish for a cure for ALS one step closer to reality. Rather than buy birthday gifts for her celebration, Cassandra asked her friends and family to make a donation to The ALS Association.

In turn, Cassandra was thrilled to present a gift of nearly $1,500 to The Association in loving memory of her grandfather, Eugene Peterson. Known as "Buppa," Cassandra's grandfather passed away from ALS when she was very young; however, Buppa sparked something special in his granddaughter. He touched her life in ways he would not have imagined. "He means everything to me, and I only wish that he could have seen how much I have grown up and accomplished," shared Cassandra.

Indeed, Buppa, who was an avid golfer, would be very proud of his granddaughter. As a junior at Pentucket Regional High School in Massachusetts, Cassandra plays varsity softball and field hockey and junior varsity basketball. She dreams of playing softball in college.

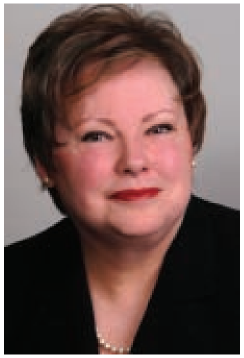
Cassandra's enthusiastic embrace of her bright future is tempered with the wisdom of someone beyond her 16 years, "The only thing I want everyone to know is that I don't take anything for granted because tomorrow it might not be there. There isn't one day that goes by that I don't think about Buppa and how much I miss him. If I had one wish it would be to find a cure for ALS, so another little girl doesn't have to lose her grandparent to this horrible disease," Cassandra declared.

Through the generosity of remarkable young people like Cassandra, The ALS Association is hopeful that one day soon, ALS will not take a beloved grandfather from the arms of his granddaughter. To learn more about how you can support The ALS Association, please call 888.949.2577, or visit our web site, alsa.org

Cassandra Koegel

Jane H. Gilbert

Appointed President and CEO by ALS Association National Board of Trustees



Jane H. Gilbert

Jane H. Gilbert joins The Association after serving as the senior vice president for chapter operations for the American Red Cross in Washington, D.C. from 2005-2008.

"We are very fortunate to have found a professional of the highest caliber in Jane Gilbert," said Allen L. Finkelstein, chairperson of The Association's National Board of Trustees. "She has an extraordinary record as a proven and widely respected leader and her accomplishments in fundraising, operations and strategic planning are strengths that will be critical in our drive to conquer Lou Gehrig's Disease."

"My most important priorities," Gilbert said, "are to intensify our aggressive focus on finding new treatments and a cure for ALS while we rededicate ourselves each day to providing the best and most compassionate care for people with ALS across our nation."

Neurology and Neurosurgery Program at Mayo Clinic Named at Top in *U.S. News* Best Hospitals Honor Roll

Mayo Clinic team members are: (left to right) Julie Hovda, RN, Dr. Edythe Strand, speech pathology, Kari Krein-Jones, speech pathology, Kelly Curtis, social worker, Dr. Brian Crum, Dr. Eric J. Sorenson, and Adele Pattinson, dietician. Other team members not show are: Darlene Graner, speech pathology, Dr. Margaret Moutvic and Dr. Kathryn Stolp, physiatry (PMR).

Advocacy Delivers the Roadmap to a Cure

by Patrick Wildman

The ALS Association's Advocacy efforts are securing historic victories in Washington, D.C. that are advancing our mission and creating the roadmap that will lead us to a treatment and cure for Lou Gehrig's Disease.

Last fall, we helped to enact the ALS Registry Act, which authorizes the Centers for Disease Control and Prevention to establish the first ever nationwide ALS patient registry. We also secured an additional $5 million to fund the registry, nearly double the funds in from 2007. The registry may become the single largest ALS research program ever created and will provide researchers with unprecedented new information about the disease that can help us improve care, learn what causes ALS, and find ways to diagnose, treat and possibly even prevent the disease from occurring.

As research continues to find that our heroes serving in the military are twice as likely to die from ALS, The Association secured an additional $5 million for the ALS Research Program (ALSRP) at the Department of Defense (DOD). A total of $10 million had been provided to the ALSRP, which is the only ALS-specific program at the DOD and is focused on translational research, with the explicit goal of finding new treatments for ALS.

In addition, The Association helped to champion new regulations implemented by the Department of Veterans Affairs in September 2008 that deliver more than $500 million in health and disability benefits to veterans with ALS, their families and survivors. The new benefits, which include as much as $8,000 per month in disability compensation, full health care, and monthly compensation for survivors, are available to all veterans with ALS, regardless of when or where they served in the military or when they were diagnosed with the disease.

And we worked with Congress to appropriate $2.5 million to fund the Lifespan Respite Care Act. This is the first time Congress has ever funded this critical program, which will expand the availability of respite care so urgently needed to improve the lives of people with ALS and their families.

These achievements could not have been accomplished without the active participation of the entire ALS community who reached out to Congress and put a face on this disease at The Association's National ALS Advocacy Day in Washington and in their hometowns throughout the year. Your contributions support this and many other ALS Association activities. Most importantly, your contributions are making a real difference in the lives of people living with ALS across the country.

Tom and Catherine Swift of the Jim "Catfish" Hunter Chapter (NC) joined advocates from across the country at National ALS Advocacy Day in May 2008. Their efforts to put a face on this disease are helping The ALS Association create the roadmap that will lead to a treatment and cure for ALS.

The Neurology and Neurosurgery Program at the Mayo Clinic in Rochester, Minnesota, home to one of The ALS Association's 34 Certified Centers of Excellence^{SM}, has been named the number one program in the country according to *U.S. News* Best Hospitals Honor Roll.

The ALS Association's Certified Center Program sets the national standard for clinical care for people living with ALS and their family members. Centers of Excellence provide state-of-the-art, multi-disciplinary ALS care and services in a supportive, family-oriented atmosphere with emphasis on hope and quality of life while living with the disease.

"The Mayo Clinic's relationship with The ALS Association allows us to provide the highest level of care to our ALS patients," said Eric Sorensen, M.D., Medical Director at the Mayo Clinic. "By complimenting our multi-disciplinary care team with the resources available through The Association, we ensure that our patients receive the services necessary for themselves and their caregivers."

"It is gratifying that so many of The Association's Certified Centers are housed at the nation's leading hospitals," said Sharon Matland, The ALS Association's vice president for Patient Services. "Working with the nation's top clinicians, we know we can provide people with ALS access to the best care available. We salute the Mayo Clinic and the other institutions nationwide that are home to our Certified Centers, for their top rankings in the *U.S. News* Honor Roll."

ALS Association Program Helps People with ALS Communicate by Janet Young

With grant support from DynaVox Technologies, The ALS Association's comprehensive Assistive Technology Consultation Program provides valuable education and training to staff at The Association's Chapters and Certified Centers℠ of Excellence on the myriad communication issues and augmentative/alternative communications devices to help people with ALS during each stage of progression of the disease.

"We have found that when people with ALS lose their ability to communicate, they often become disconnected from the world around them," shared Sharon Matland, vice president for Patient Services. "One very important way we can help patients continue to communicate and stay connected is by providing information, education and support on augmentative communication and the resources available in the market place. The program, led by Alisa Brownlee from The ALS Association's Greater Philadelphia Chapter, provides this kind of valuable information and is a resource not only to staff at our chapters, centers and clinics, but to any medical professional working with people with ALS.

Sponsored in part by DynaVox Technologies, a provider of communication solutions for people with ALS, the Assistive Technology Consultation Program provides practical tools to help chapter, center and clinic staff in their day-to-day work related to the challenges people with ALS face as they lose their ability to speak. Among the components of the program are a special Assistive Technology electronic bulletin board for chapter, center and clinic staff to post questions, information and resources to help patients secure reimbursement for augmentative communications devices, and ongoing clinical and technical support for speech-language pathologists and assistive technology specialists nationwide.

Commander Steven Stacey, third from left, with his naval training team.

Troops in Iraq Help to Fight ALS in the U.S. by Dan Gordon

As executive officer of the Naval Training in Team in Umm Oasr, Iraq, CDR Steven Stacy was a long way from home when he learned of his father's death from Lou Gehrig's Disease. But as he mourned from afar, Stacy discovered he wasn't alone.

In a moving show of their support, members of Stacy's 70-person unit, which consisted of both U.S. and British services, organized a Christmas raffle, with all proceeds split between a UK charity and a U.S. charity – The ALS Association. As a result of the event, Stacy was able to send a check to The Association in honor of his father, Donald C. Stacy.

"Having the support of my command was truly a blessing and something that I will never forget," Stacy said.

When Stacy first learned of the diagnosis, he visited The ALS Association's web site. "After reading the literature on The ALS Association web site, even I could have diagnosed him with ALS," he said.

Stacy realized the days he had left to spend with his father were numbered. He took time to more fully appreciate his father's qualities. "He was a quiet, thoughtful, and caring person you could always count on," Stacy says. "Through his example I learned to slow down a little, look, listen, analyze, and then act. His teachings have served me well in the Navy as well as in life."

Donald Stacy

It's said that in peacetime sons bury their fathers and in wartime fathers bury their sons. "As I headed to war I couldn't help but wonder who would win this race," Stacy recalls. The answer came only two months into his year-long tour: Donald Stacy had passed away in the night.

In directing his unit's generous support to The ALS Association, Stacy hopes to promote a greater awareness about Lou Gehrig's Disease, particularly among the general medical community. "Without a diagnosis it is very difficult to get proper care and treatment," he says.

"The ALS Association provided a guiding light for me personally," Stacy says. "The information on the web site, along with the booklets on ALS, not only helped me cope with the changes taking place in my father, but helped my daughters understand what he was going through and not be afraid."

Charitable Gift Annuities—When You Can Give *and* Receive

Gerald Ross was only four-years-old when Lou Gehrig became a New York Yankee in 1925. That year, Gehrig began his record-setting consecutive game streak of 2,130 games, earning him the nickname "Iron Horse." Gerry, a life-long baseball fan, vividly remembers sitting by the radio in his home in Michigan as Gehrig delivered his famous "luckiest man" speech on July 4, 1939.

An iron horse himself, Gerry is still working at 87 years of age, representing furniture and lighting companies as he has for more than 50 years. When a colleague of his died recently from ALS, Gerry sought to combine his passion for doing some good for others," with his desire to pay tribute to his friend, by establishing a charitable gift annuity with The ALS Association.

> *"All of us are in need of something, and all of us can give something."*
>
> *–Noah benShea*

Gerald Ross

A Charitable Gift Annuity Makes Dollars and Sense

In the current period of low interest rates and a volatile stock market, charitable gift annuities are growing in popularity. To create a charitable gift annuity with The ALS Association, a donor gives cash, stock or other assets, a minimum of $10,000 worth to The Association. In return, the donor receives a fixed payment for life, and a sizable tax deduction.

Gerry feels good about supporting the search for a cure for ALS and getting paid for it. To find out how you can celebrate the life of someone special through a charitable gift annuity, please contact David Moses, director of Gift Planning, at (888) 949-2577, ext. 212, or dmoses@alsa-national.org. You can also learn more about gift annuities by visiting The Association's web site at www.alsa.org/giftplanning. All inquiries are strictly confidential.

Charitable Gift Annuity Rates*
Single Life

Age	Rate
65	5.3
70	5.7
75	6.3
80	7.1
85	8.1
90+	9.5

*Suggested rates established by the American Council on Gift Annuities. For illustrative purposes only. Rates are subject to change.

☐ **I am interested** in learning more about charitable gift annuities. Please contact me.

☐ **I would consider** remembering The ALS Association in my will, trust or other estate plan.

☐ **I have already remembered** The ALS Association in my will, trust or other estate plan.

NAME ______

MAILING ADDRESS ______

CITY ______ STATE ______ ZIP ______

PHONE ______ E-MAIL ______

Mail the completed form to:
Director, Gift Planning
The ALS Association
27001 Agoura Road, Suite 250, Calabasas Hills, CA 91301-5104
Or visit www.alsa.org/giftplanning or fax to: (818) 880-9006

Yachtsman with ALS Wins Beijing Gold

Paralympic champions Nick Scandone, who unfortunately succumbed to ALS in January 2009, and teammate Maureen McKinnon-Tucker, who was paralyzed after a fall, are shown here in September 2008 after they clinched the Gold Medal in the SKUD 18 sailboat racing competition of the Paralympic Games in Beijing, China. Scandone displayed exceptional courage by competing for several years after his ALS diagnosis.

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Dated Material

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Baseball Knocking out ALS

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campaign marking the 70th anniversary of the speech and encouraging donations.

"We are honored and pleased to have the opportunity to join these four important organizations in an attempt to make progress in the fight against ALS, a disease that is associated with one of the greatest players in baseball history," said Major League Baseball Commissioner Bud Selig.

"Minor League Baseball has worked with The ALS Association for six years as one of our primary Charity Partners," said Minor League Baseball President and CEO Pat O'Conner. "We are pleased to continue this worthy endeavor and welcome the opportunity to join forces with the other outstanding organizations to bring more national attention to ALS."

Event day highlights include players and celebrities reading the speech. MLB.com also will conduct an online auction to raise funds. The Association's national network of chapters also will be sponsoring its own special fundraising programs.

"For the first time in history, ALS is being recognized and tied to something common amongst all of us, baseball," said former Boston Red Sox pitcher Curt Schilling, who named one of his sons Gehrig, and along with his wife Shonda has raised nearly $8 million for The Association. "Unfortunately baseball is why we know about Lou Gehrig's Disease, and it's been too long in coming, but it's finally here and that's all that matters. Making July 4th '4♦ALS Awareness' means that every year we'll be able to raise money for research and increase awareness."

Curt Schilling, former Red Sox pitcher.