

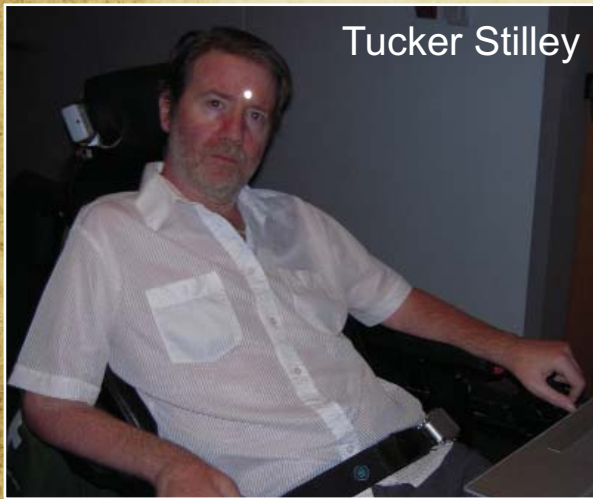
# THE MESSENGER

The ALS Association Greater Los Angeles Chapter

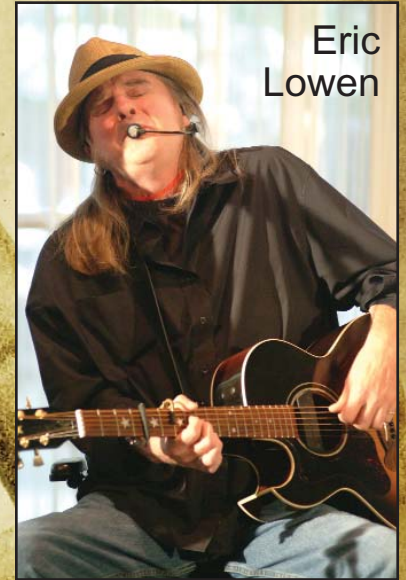
Winter 2008

## Artists with ALS

A musician, a filmmaker, and a multimedia artist keep working and creating despite Lou Gehrig's disease.



Tucker Stillely



Eric Lowen

## PLUS +

Three Major Public Policy Victories  
Tom Horton Paddles with Sharks  
Eyetracking Systems Help PALS  
Sheriff's Deputies Run for Charity  
IRA Tax Benefit Restored  
Support Group Calendar  
Research Updates

AND MORE



Scott Lew



**Greater  
Los Angeles  
Chapter**



## Looking Back While Moving Forward



*Editor's Note: Among other highlights, 2008 marked the Chapter's 20th Anniversary. To celebrate the occasion, we created a special issue of The Messenger this past Spring with quotes from some of the people who have been instrumental in our growth and success. As this 20th Anniversary year comes to a close, we thought it fitting to publish one of those interviews, our conversation with the Greater Los Angeles Chapter's Board Chair, Kathleen Rasmussen, who also served as a Trustee for five years.*

**W**hat do you think have been some of the more dramatic areas of change or growth the Chapter has experienced since you've been involved?

Oh, I think it has been in every area of our mission. First, we're very, very proud of the improvements in the patient services that we offer our PALS. Secondly, the number of case managers that we have and the amount of time they spend with our PALS. Probably at the forefront is also *The Center for ALS Care* at Cedars-Sinai and Loma Linda. Thirdly, our fundraising has increased dramatically also – we're certainly raising a lot more money for patient services and for research. Fourthly, we've expanded our territory to seven counties. Finally, the amount of awareness and publicity we've gotten for the Chapter has increased dramatically. So I think across the board we've grown so much. I am very proud of the growth and development we've experienced.

I am also very, very proud of the people associated with the Chapter. I look to many, many people who have made our success possible – my predecessor John Krave; his predecessor Carol Econn; Cecile Falk-Balser; of course the staff that's currently in place, Fred and Giovanna; the Board and the Advisory Board of Trustees, and all the others. There are so many people, volunteers and staff members, who give 150% of themselves to the Chapter. I really am just so proud of the team that we have and the efforts that we make.

*What are some of the moments that have been inspirational or touched you personally in some way?*

Some of the individual meetings I've had with PALS, seeing the difference we can make in their family's lives, their quality of life. The opening of the *Center for ALS Care* in Cedars-Sinai

certainly stands out as one of the bigger events. Seeing the Chapter featured on *Entertainment Tonight* and the *Today Show* and some of the other national television this year has been very exciting. Probably hosting our first gala, which I co-hosted with Lynn Safenowitz and Louise Rice at the Playboy Mansion a few years ago was certainly a highlight also.

*What is it about your experience serving in a leadership capacity that has been especially memorable?*

I think that the opportunity to work on the strategic plan for the Chapter. I worked on the first one a few years ago and I look forward to doing a new one, and really, having some influence over setting the future goals and the future direction of the Chapter is very exciting.

*What are some of the Chapter's goals for the future?*

Primarily, the goals that we're focusing on this round are reaching at least 80% of the PALS in our service area, and determining the best standard of care for ALS patients so that all the patients – hopefully this will become a national program – so that all patients have the best care. Also working on advocacy within the State of California. The ability of ALS patients to get funding for patient care from the State government is extremely important.

*You and your husband, Dean, give a significant amount of money to the Chapter, but you also give a tremendous amount of volunteer time and effort. What keeps you going?*

I cannot imagine anything more horrific than being diagnosed with ALS. The mystery of what causes ALS really frustrates me. I just believe that the difference that I will make in this world is fighting to find a cure and providing the best care for ALS patients, and I hope that will be my legacy.

### Calendar of Events

**Greater Los Angeles Chapter Annual Meeting**  
Tuesday, February 10, 2009

**National ALS Advocacy Day and Public Policy Conference**  
Sunday, May 10 - Tuesday, May 12, 2009

**San Bernardino/Riverside County Walk to Defeat ALS™**  
Sunday, April 26, 2009

**Ventura/Santa Barbara County Walk to Defeat ALS™**  
Sunday, May 3, 2009

**Strike Out Lou Gehrig's Disease Baseball Tournament**  
Thursday, July 23 - Sunday, July 26, 2009

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### President Bush Signs ALS Registry Act

The law signed October 8 establishes the first-ever national ALS patient registry at the Centers for Disease Control and Prevention.

Under the ALS Registry Act (s. 1382), the Centers for Disease Control and Prevention will collect information on ALS patients nationwide. It is hoped the data will contribute to understanding the cause, treatment and cure of Lou Gehrig's Disease.

The ALS Association has been working with Congress for nearly four years to pass the ALS Registry Act, which was first introduced in 2005 by Senate Majority Leader Harry Reid (D-NV), Senator John Warner (R-VA), and U.S. Representatives Eliot Engel (D-NY) and Lee Terry (R-NE). Thanks to their leadership, the bill passed the U.S. Senate and the House of Representatives with near unanimous support in late September. Congressman Eliot Engel's grandmother, Dora Engel, is believed to have passed away as a result of ALS.

The ALS Registry Act enjoyed broad bipartisan support in Congress because of the grassroots efforts of thousands of people with ALS and their families who reached out to Congress. Individuals like Kate Linder, star of the daytime

television program, "The Young and the Restless," also helped raise awareness and build support for the bill among the public and lawmakers alike.

"This will truly make a difference in the lives of thousands of people with ALS and those yet to be diagnosed, including our military veterans, who are at greater risk of ALS," said Linder, whose brother-in-law Scott was diagnosed with ALS in 2004.

The ALS Association Greater Los Angeles Chapter will keep you updated on the latest developments, but we need our readers and advocates to stay involved because we must work with Congress to secure funding for the registry.

In the meantime, please remember to thank your Members of Congress! Let them know that the ALS community appreciates their support. Thank-you letters you can send are available in The ALS Association's Advocacy Action Center at <http://capwiz.com/alsa/home/>.

Read more on the Greater Los Angeles Chapter's website, [www.alsala.org](http://www.alsala.org).

### VA Grants Benefits to All Veterans with ALS

On September 23, the Veterans Administration passed regulations granting numerous benefits to all veterans with ALS without their having to prove their disease was caused by service in the military.

The new policy applies to all veterans diagnosed with ALS regardless of when or where they served or when they were diagnosed with the disease following their military service.

This tremendous victory represents the culmination of years of work by The ALS Association, the Greater Los Angeles Chapter, and veterans across the country. Our outreach efforts - testifying before Congress, partnering with the VA, advancing research to identify the connections between ALS and military service, and educating the public about this issue - have paid off.

The ALS Association has been the leading organization advocating for this policy change at the VA for many years. In 2001, The Association strongly supported the VA's decision to grant benefits to veterans of the 1991 Persian Gulf War and has championed legislative efforts to build on that policy so that it applies to all veterans with ALS.

"ALS is a disease that progresses rapidly, once it is diagnosed," said VA Secretary James Peake. "There simply isn't time to develop the evidence needed to support compensation claims before many veterans become seriously ill. My decision will make those claims much easier to process, and for them and their families to receive the compensation they have earned through their service to our nation."

According to studies, military veterans are nearly twice as likely to develop ALS as those with no history of military service, regardless of where or when they served in the military.

We again would like to thank all veterans for their efforts to advocate for this vital benefit.

Visit [www.alsala.org](http://www.alsala.org) for more information on services for veterans with ALS.

### Congress Gives Additional \$5 Million for ALS Research at Department of Defense

FY 2009 Appropriations bill funds DoD's first ALS-specific program.

The Department of Defense's *ALS Research Program (ALSRP)* is focused on translational research with the goal of finding new treatments for ALS.

The funding is an especially significant victory not only because very few funding bills even passed Congress this year, but also because of the significant amount of competition for scarce federal dollars.

The \$5 million will be available to ALS researchers across the country. Moreover, the collaboration facilitated by the ALSRP and the additional money will

provide the ALS community with greater opportunities to develop meaningful treatments.

While this is the first time Congress has ever provided funding for the ALSRP, the program was initially developed last year when The ALS Association partnered with DoD to bring new focus to their ALS research portfolio, which we originally helped to start more than five years ago. The Department of Defense program was modeled after The ALS Association's *TREAT ALS* (Translational Research Advancing Therapies for ALS) research initiative.

# Eric Lowen Learns How to Travel with ALS

Despite the disease that left him with little control over his body, the professional musician continues to play and record music, tour with his band, and take skiing and swimming vacations with his family.

By James Klein, Editor

**E**ric Lowen was diagnosed with ALS in 2004, and now relies on a motorized wheelchair and other assistive devices, as well as the help of friends and family, to maintain a busy personal and professional life. Despite his physical challenges, the singer, songwriter and guitar player travels extensively with his band and takes vacations with his wife and their five children.

"It's a progressive disease so you learn a little at a time, and I've been going on tours steadily," explains Lowen. "I travel once a month, so I've learned a lot about traveling with ALS.

"For example, to get to the airport, Super Shuttle provides disabled transport and they don't charge you any more than you would get charged otherwise."

Lowen advises, however, that PALS be prepared to pay extra for renting equipment and other assistance while traveling. But he insists it is not difficult to arrange even extensive travel plans. The key to traveling with ALS, Lowen stresses, is to start planning your trip as far in advance as possible, and to seek help from The ALS Association's many chapters.

"I started almost a month before I left," he recalls. "I contacted ALS Association chapters, and in the case of Quebec, it was the ALS Society in Quebec. They're all very willing to help in any way they can. They referred me to caregiver companies in each city I was going to...The ALS Associations either gave me a Hoyer lift and a shower chair or arranged one for rental to be delivered to the hotel.

"I called the hotels and made sure that the handicapped equipment was right. Having space under the bed, for example. Sometimes I take bed risers, which they sell at *Bed, Bath, and Beyond* for 20 bucks, to give enough room for the Hoyer lift to fit under the bed. And making sure the commode chair is one



Eric Lowen takes a dip in a lake with his niece, Liza Cain and his stepson, Tom Ferguson

that will fit over the toilet...You want to get a handicapped room that has enough room to get into the bathroom. Preferably with a roll-in shower.

"I take a transfer board with me...and I always ask for extra pillows at the hotel to prop myself up. I took the charger for my wheelchair...I took gloves for the caregivers and wipes and stuff like that. A cervical collar is really handy when you're traveling to keep you from bouncing around too much.

"I had arranged with the airlines and made sure they knew I was coming with a power wheelchair and I needed help out of the wheelchair and into an aisle chair and out of the aisle chair and into the seat. And I needed to sit in the front bulkhead on the aisle, and have somebody sitting with me...Southwest Airlines does the best job in my experience.

"We got to the airport. We used the Red Cap at the curb, and then we had the passes all printed out. You sail right through security because they let you all go, everybody goes with the handicapped person.

"You go to the gate, check-in, and get your special things for pre-boarding. Find out how many people they'll let you pre-board with...And I use my gel pad from my wheelchair to sit on the plane so I'm comfortable.

"My wheelchair was waiting for me at the gate. I gave them instructions on how to fold the back down on the wheelchair so it wouldn't get broken and so they'd be able to fit it in."

Lowen's family ski vacation last year was made possible through companies that specialize in providing ski equipment and instruction for people with handicaps. "I used Disabled Sports Eastern Sierra, at Mammoth. They were really accommodating. It was \$65 for four hours of skiing, and it was really fun...they put me in this little, they call it an egg, and it's got skis on the front and on the back, a place for your bottom and a place for your feet. And it's got a handle on the back, sort of like a dog sled. And they strap you in there, and they bundled me up and we were off."

Lowen's recommendations for other PALS wanting to travel? "I would say one very important thing is don't be afraid to ask for help. And make sure that you're well prepared.

"Oh, and one more thing," Lowen adds. "Choose your family very carefully. If everybody's in the frame of mind to have fun, it works. The guys I travel with for my band, they don't like to travel without me because they have to wait in security lines and they have to wait to get on the plane and choose their seat and everything like that. When I go with them, we breeze right through."

*For twenty years, Eric Lowen and Dan Navarro have written, recorded and toured for a growing national audience, producing nine CDs including their highly-awaited new album, "Learning To Fall," available now through their website, [www.lownav.com](http://www.lownav.com).*

*Read more about Eric Lowen's travels, and get a list of recommended equipment and travel tips for ALS patients at our website, [www.alsala.org](http://www.alsala.org).*



# Technologies Help Tucker Stilley Create

The multimedia artist hasn't let near total paralysis stop him from producing a stunning collection of artwork.

By James Klein, Editor

For over 30 years, Tucker Stilley has worked as an artist, sound designer and film editor on everything from Hollywood blockbusters like *Armageddon* to subversive documentaries like *Sir! No Sir!* to literally hundreds of music videos.

Diagnosed with Lou Gehrig's disease in 2004, Tucker has lost the use of his limbs and now relies on his computer to create works that range from meditative paint-washed canvasses to slide-show LCD screens. The pieces collected on his website, [www.tuckerstilley.com](http://www.tuckerstilley.com), represent a broad range of media – video, music, photography, painting, collage, drawing, mixed media – there is even a graphic novel he wrote and illustrated about his struggles with ALS.

Stilley continues to work as a media editor, "In a limited sort of way. Against all odds I can still do everything that is required for the job. Of course I need an assistant, but that's not unusual for an able-bodied editor."

Though not a programmer, Tucker has developed innovative ways of combining existing computer systems and applications, which in turn have spawned ideas for new works.

"The further I got into it the more unexpected little relationships between various pieces of software popped up, things that would suggest new funny ways of working, which in turn suggest new funny little projects."

Not able to control a standard computer mouse, Stilley uses a special camera on his computer that tracks a small dot attached to his forehead, translating the movements of his head directly to the onscreen cursor. Buttons mounted on the arms of his wheelchair simulate the mouse's click buttons. Special software allows him to custom design a virtual onscreen keyboard, while another application tailors his keystrokes to the particular software he is using.

More information on the technolo-

gies Tucker uses, as well as links to his websites, can be found in the online version of this article at [www.alsala.org](http://www.alsala.org).

Stilley says of his computer systems, "I hope everything I've done becomes swiftly obsolete - then maybe we'll be getting somewhere. In the meanwhile if any of my techniques or attitudes inspires anyone I'll be a million times blessed."

He also looks forward to future medical and technical developments. "You can teach a computer program to translate brain states into desired output - words for instance or cursor control on a screen. Another trick is to route around the neural damage and convert nerve information directly into muscle stimulation. And then there's straight-up 'Borg' style trans-humanism..."

Stilley has several online projects, including another collection of his paintings, songs, videos and other expressions called *The Permanent Record of Newjack Rasputin*; and *All Hands on Board*, an ongoing blog, announcement board, and collective art space for his friends and family.

Tucker and his wife, Lindsay Mofford, a documentary filmmaker and a film and television editor, have a unique working relationship. "We have been together since our mid-teens. We have been professionally working together since our twenties," says Mofford. "Every project I have been involved in, Tucker has been there too... So for the past year, I've been only taking jobs that I can do at home. This way Tucker can still be involved in my work. Also I can be here as a caregiver and artist's assistant."

As any family member of someone with ALS knows, the extra caregiving required can be difficult to manage. "Tucker's mother has been living with us for over two years," Mofford says. "We also have many friends and family and neighbors who have all really been supportive. But it still is too much. I don't get



Photograph by James Klein

Tucker Stilley at an October, 2008 benefit for him at the RedCat Theater in Disney Concert Hall

enough sleep and it's tough to always have to make sure someone is here with him."

She credits the Chapter with helping her family through the most difficult times. "When Tucker was first diagnosed, The ALS Association Greater Los Angeles Chapter was a useful place to go to get general information. Also, we go to the clinic at Cedars and love Dr. Abi [Dr. Abirami Muthukumaran, Director of the Center for ALS Care at Cedars-Sinai Medical Center].

"We love Jan [Janet Simms, R.N.] who runs our local Support Group, which we go to several times a year. Norma [Equipment Loan Pool Specialist Norma Segura] and the loan closet have been quite useful and terrific. The caretaker seminars are also pretty good."

What advice would she give to other families coping with ALS? "Try not to worry about the future and just take it one day at a time. Love him or her for what he/she can do today not what one used to be able to do or might not be able to do. Hold their hands, look them in the eyes and give them the strength to face the scary diagnosis. This action will also give you, the partner, the courage to get through it. Accept all the support that friends and family want to give... and take a break without feeling guilty."

# Scott Lew Keeps Laughing

The film producer, writer and director finds humor even in the midst of fighting Lou Gehrig's disease.

By James Klein, Editor

The funny thing about Scott Lew is how funny he is. It is clear from watching *Living with Lew*, a 2007 documentary film about him, that someone who is as naturally funny as Scott doesn't suddenly lose their humor when they are diagnosed with ALS. They rely on it, in fact.

"I think funny is just a great way to jiu-jitsu reality," Scott says in the film. He also espoused the benefits of humor during a recent interview with the Chapter. "When you're facing a disease like ALS, you want to keep your sense of humor," he says. "You want to have a positive attitude, and the best way to do that is to look on the bright side. Plus, you can use the darkest part of humor. With ALS, it's true, we also have a dark humor to fall back on."

Scott also describes how paradoxically ALS has in some ways given him a more positive view of life: "I'm sure you've heard other people with ALS say this. We've got this special view of the positive side of other people. The less you can do for yourself, the more you're amazed how other people step-up to help you. That's something you appreciate when you have ALS."

*Living with Lew's* director, Adam Bardach, does not avoid the realities of ALS, but artfully balances more sobering moments with equal measures of Scott's indomitable personality.

"You're faced with a choice," Scott says in the film. "You can be miserable, or you can just live your life as fully as you possibly can..."

Despite its humor, there are times during *Living with Lew* when even Scott can't stop the tears, including a moving scene in which he describes his success completing *Bickford Shmeckler's Cool Ideas*, a 2006 film he wrote and directed, while combating ALS.

"A lot of it is being able to depend on the people around you. I think you walk around trying to be really self-reliant, and

then when something happens and you're falling apart, you can't be. It's just amazing that everybody really comes through for you."

Scott's wife, Ann Lew, recalls the day in 2003 when they received a definitive diagnosis of ALS: "Scott and I knew a lot about what was going to happen to us, in the way that we damn well better enjoy everything we have now..."

In an interview with the Chapter, Ann says of living with someone who has Lou Gehrig's disease, "The greatest challenge is, I guess you think that because the illness is progressive, you're never done...You think you've got things figured out, and the next month it's something else."

"Ann is a tremendous help," Scott says in *Living with Lew*. "It's like she has ALS because I have it...and the way she deals with it is remarkable. Ann has absolutely been my whole existence. She always was my better half. Now she's my better half with the muscles. She's being two people. She is using her body for two people. That's just incredible. I'm so lucky."

One of the experts interviewed in the film stresses the importance of families in the support of ALS patients: "The disease is too great to be suffered alone, and for patients who have family, especially if the family is loving and supportive, the disease seems to be able to be tolerated with joy. That's because everyone in that family is carrying part of the burden."

Scott's nephew, Dillon Plageman, competed this summer in the Chapter's baseball tournament, the *CytRx Strike Out Lou Gehrig's Disease All Star Invita-*



Adam Bardach and Scott Lew

*tional Tournament*, which raises money to fight ALS, and accompanied the Chapter's President and CEO, Fred Fisher, during the check donation ceremony on the field of Dodger's Stadium.

Scott also credits the Chapter and its Case Manager, Martha Mowatt, with supporting him during the illness. "She's really been helpful," he says.

In addition to writing and directing *Bickford Shmeckler's Cool Ideas*, Scott has worked as a film executive, including a stint as Director of Development for Beacon Pictures, has produced and directed documentaries, written for television, and currently has three series pilots at ABC. He is also working on a book about his experiences in the film industry called *Scott Lew: Hollywood Deadly*.

The producers of *Bickford Shmeckler's Cool Ideas* took no fees in the making of the film and are donating their share of revenues to ALS charities. The production company behind the film, Vulcan Productions, is also donating a sizable share of revenues to ALS charities.

"Luckily, I chose a type of work that allows me to keep going," Scott told the Chapter. "I encourage anybody with ALS or any kind of muscular disease, to find something creative to express themselves. You can find ways to do it, whether it's writing or something else."

More on *Living with Lew* can be found at [www.livingwithlew.com](http://www.livingwithlew.com). The website for *Bickford Shmeckler's Cool Ideas* is [www.bickfordmovie.com](http://www.bickfordmovie.com).

A longer version of this article with more photographs can be found on the Chapter's website at [www.alsala.org](http://www.alsala.org).

# Astrocyte Replacement Shows Promise in a Rat Model of ALS

In amyotrophic lateral sclerosis (ALS), the cells affected in the disease, the motor neurons, have extremely long processes that need to be appropriately connected with the muscles they innervate, making motor neuron transplantation a daunting task.

Over the past years, however, increasing evidence supports the notion that not only are motor neurons affected in the disease, but also their surrounding cells, including astrocytes, which are important cells that regulate glutamate concentrations (required for normal function but if abnormally increased become toxic to the cells).

In a study published this week in *Nature Neuroscience* and led by The ALS Association-funded Nicholas Maragakis, M.D., investigators demonstrate in a rat model that a feasible approach to increase survival in these animals is to transplant astrocytes. Although a great deal still needs to be done to apply this approach in the clinic, these studies do provide compelling evidence that this may one day be feasible.

Investigators isolated astrocyte precursors from developing spinal cord and transplanted these into the cervical spinal cord of 90 day old rats carrying the G93A SOD1 mutation. Investigators chose the cervical region with the hope that these transplants would have benefit for motor neurons that project to the diaphragm muscle. Loss of these neurons ultimately effects the survival of people with ALS.

These transplanted cells survived, differentiated into mature astrocytes, and interacted with motor neurons in the spinal cord. Interestingly, these trans-

planted astrocytes did not show any overt signs of damage related to their close proximity with neurons producing mutant SOD1 motor neurons. This is an interesting finding as one may have expected that toxic factors released from the mutant expressing cells may damage the transplanted cells. Transplanted astrocytes delayed disease onset as well as progression of disease by about two weeks.

Several contributors may have led to the increased survival. Increased levels of the glutamate transporter GLT1 (found exclusively on astrocytes) which have been previously shown to be decreased in people with ALS and is replicated in the animal models may account for the increased survival. Astrocytes also produce trophic factors which support the survival of motor neurons. However in these transplants, investigators could not find increased levels for a variety of tropic factors they measured in the spinal cord including IGF1, BDNF and VEGF. Instead the investigators identified that there was a reduction in microglia, the inflammatory cells in the brain which may have contributed to the increased survival.

"In this study, we have been trying to design a paradigm which could be eventually translated to ALS patients. That is why we focused on a region, the cervical spinal cord, where respiratory function is centered. Our findings suggest that targeted cell replacement of cells other than motor neurons may be promising, and targeting astrocyte-relevant pathways in other ways may be important in ALS therapeutics as well," commented Nicholas Maragakis, M.D.



## Researchers Identify Protein that Controls Neuron Development

By Richard Robinson

Researchers funded by The ALS Association have identified a key protein that controls how stem cells in the brain become upper motor neurons. Upper motor neurons are the nerve cells in the brain that degenerate in ALS.

"This important finding will allow us to better understand how motor neurons develop in the brain," said Lucie Bruijn, Ph.D., Senior Vice President, Research and Development of The ALS Association. "This is vital information as we try to understand the causes of ALS and as we develop new treatments targeting motor neurons."

The researchers examined brain development in mice, and focused on a protein called Bhlhb5. While the protein had been previously identified, its role in development was unknown. They discovered that the protein was needed to turn brain stem cells into upper motor neurons. Bhlhb5 acts within the cell's nucleus, turning on and off other genes that build the cell into a motor neuron.

Upper motor neurons link the brain's cortex to the spinal column. Signals sent through these neurons control muscle movements. In ALS, these neurons die off (along with the lower motor neurons of the spinal cord), leading to paralysis. Much less is known about the development of upper motor neurons compared to lower motor neurons, making the findings from this study especially significant.

The research team was led by Jeffrey Macklis, M.D., of the Department of Stem Cell and Regenerative Biology and the Harvard Stem Cell Institute at Harvard University in Cambridge, MA, and Lin Gan, Ph.D., of the Center for Neural Development and Disease at the University of Rochester, Rochester, NY.

The work appears in the October 23, 2008 issue of the journal *Neuron*.



## Commitment and Camaraderie Drive Kern Walk Community

The Kern County *Walk to Defeat ALS™* was a triumph of spirit and support on Saturday, October 4, 2008.

By Dawn Muroff

The clouds above Park at River Walk threatened rain, but they had no influence whatsoever over the crowd of volunteers that busily prepared for the 5th Annual Kern County *Walk to Defeat ALS™*. As the banners were hung, the PA system tested, information displayed, and the registration table readied, the commitment driving this community was undeniable. The energy continued to build as the thirty walk teams began to arrive, and the rainbow of team shirts filled the landscape. From (Grandma) Bert's Bunch to Mike's Miracles to Linda's Loonies, each group was soon experiencing the special camaraderie and profound sense of purpose that this day engenders. Families designed signs in honor or memory of beloved PALS, and face painters got busy creating works of art on the younger set. Nearby, an ALS Advocacy banner was quickly filled with messages of hope and dedication, and walkers took the extra step to register as ALSA advocates.

Before everyone set off on the walk itself, the flag salute was lead by a local Boy Scout troupe and words of thanks were shared by Walk organizer, Stacy Inman, and her husband, PALS Mike Gagner. The many event sponsors were then acknowledged, and awards were presented to the five walk teams who have been with the Kern County Walk since its inception. Fred Fisher, President and CEO of The ALS Association Greater Los Angeles Chapter, expressed his gratitude to everyone gathered and informed them of the direct impact that their fundraising efforts would make on patient services and research. He also spoke of the extraordinary legislative victories we had made over the last two weeks, due to the dedication of ALS Association advocates. Local cheerleaders led the teams in stretches, the balloon arch was cut, and the spirited journey around the park began.



Michael Gagner Crosses the Finish Line with the Mike's Miracles Team

As everyone completed the walk, lunch was served, and a Dixieland jazz band filled the air with celebratory sounds. A massage therapist was even available to soothe any aching muscles. As the event drew to a close, it was evident that Mike and Susan, and their incredible crew had given attention to every detail...including holding off the rain until everyone left the park!



### 2008 Kern Walk Team Captains

Candle Crew for Crystal Vela: Carolyn Bedford  
Bud's Buddies: Brenda Bibee  
Hazel's Crew: Paul Collins  
Uncle John's Crew: Ella Flores  
Gals for Pals: Ruth Gentelia  
Linda's D'Feeters: Linda Gilli  
Dean: Laura Graves  
Mike's Miracles: Stacy Inman  
Munger's Angel: Leslie Jiles  
Neil's Diamonds: Jessica Massey  
Sandy's Soldiers: Sandy Oliver  
Parks Pals: Cris Parks  
[Team Unknown]: Sam Saks  
Rick's Rebels: Mark Sharp  
Royally's (Roy Lee): Melyssa Springmeyer  
Pat's Pals: Lya Vallat  
Roy's Team: Angela Ward  
Gordies Groupies: Derek Weidman  
Linda's Loonies: Tamala Wood  
Cory's Crusaders: Vicki Yaeck

Everyone involved in the Kern County Walk to Defeat ALS had a great deal to be proud of. Not only did they raise \$81,000 dollars – they also raised spirits, hope, and ALS awareness within their community. Thank you, Kern County – that's no small feat!

### 2008 Kern Walk Sponsors

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# Supporters Show Their Love at Los Angeles County Walk on October 26, 2008



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 We Belong Together...for Eric Lowen:  
 Terry Brooks  
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 JD: Nicole Carrico  
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 Jennifer Concepcion  
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 Team Doran: Diane Doran  
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 Jinah Kim:: Jinah Kim  
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 & Richard Kraft  
 Bruce Almighty: Michael Laubenstein  
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 Z Team: Nancy Leininger  
 Fight On for Melissa: Alicia Liotta  
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 Shannon: Courtney Shannon  
 Cruisin' with Danny: Brandi Shikuma  
 Team Rosene: Shaina & Nikki Shultz  
 Walter's Walkers: Nancy Skowron  
 Marching for Marlis: Bonnie Sloane  
 Royal High School Interact: Samantha Snyder  
 Ken's Corps: Roger Spencer  
 Harry's Heartbeats: Ricki Stein  
 Rita's Robbins: Sue Sterry  
 Carl's Crusaders: Stephanie Stokes  
 Discovery Prep Boys Basketball: Steve Stokes  
 Emerald Isle: Seth Stuart  
 For Dad Team: Eileen Sullivan  
 Teddy: I.H. Sutnick  
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 Cigna Group Insurance: Korie Telfare  
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 Andy's Navy: Kimberly Tsuchiya  
 Pals For Life: Elizabeth Uyehara  
 Daniel Valle: Steve Valle  
 Yell in Support of Michele!: Jessica Vroman  
 Phi Delta Theta: Matthew White  
 Barb's Bunch: Reid Wilbraham  
 Carlton's Crew: Patty Zuber

# Seeing the Benefits of Eyetracking Technology

CART's Corner: Rancho Los Amigos National Rehabilitation Center

By Andy Lin, Technology Specialist, Center for Applied Rehabilitation Technology (CART)

**E**yetracking systems utilize eye movement to operate a computer or a computer-based communication device. In the past few years, eyetracking has become a more viable access tool due to improvements in the technology that have resulted in more accurate, smaller, and easier to use systems. From reports on television news programs to vendor sessions at disability conferences, eyetracking is being talked about in many circles.



ALS patient Mike Toennis with LC Technologies' Eyegaze eyetracking technology

### What is eyetracking and how does it work?

Eyetracking systems send infrared light to the eyes through infrared cameras. This light is reflected off the eyes and is captured by infrared receivers incorporated into the system. Special software analyzes this information and translates it into specific movements on the computer or the communication device's screen.

In simple terms, the eye acts as a mouse. Blinking or hovering over a section of the screen allows the user to perform functions like clicking or double clicking the mouse. Most systems are able to track both eyes, resulting in better performance.

### Is eyetracking appropriate for me?

Despite its growing popularity, eyetracking may not be appropriate or ideal for everyone. In many instances, simpler and/or lower-tech solutions may benefit PALS who are having difficulty using their computer and/or communicating with those around them.

When considering a communication tool for a PALS, whether it is eyetracking or another solution, it is important for the PALS to be referred to an assistive technology center such as CART, or a clinician who specializes in Assistive Technology. This is recommended as there is not enough objective research available that compares the performance of the various eyetracking systems.

### What systems are available?

Listed below are five commercially available eyetracking systems. Each system has different features and functions available. Based on my personal experience, the Mytobii system is most tolerant of head movement and easiest to calibrate. This does not mean that it is the best system for everyone as there are other factors that must be considered. Often times, a system that may work well with one person may not work as well with another. The systems range



ALS patient Dr. Rahamim Melamed-Cohen uses EyeTech's TM2 eyetracking system

in price from \$7,000 to \$15,000. Insurance may help with the cost. Visit the vendor websites for more details.



PALS Birgit Krumschmidt using Mytobii's P10 eyetracking tool

### Eye Response Technologies

#### "ERICA System"

<http://www.eyerresponse.com>

#### EyeTech Digital Systems

##### "EyeTech TM3"

<http://www.eyetechds.com>

#### LC Technologies

##### "Eyegaze"

<http://www.eyegaze.com>

#### Mytobii

##### "Mytobii P10"

<http://www.tobiiati.com>

<http://www.infogrip.com>

#### Dynavox

##### "Eyemax"

<http://www.dynavoxtech.com>

Andy Lin is the technology specialist at the Center for Applied Rehabilitation Technology (CART) at Rancho Los Amigos National Rehabilitation Center, in Downey, California. If you have questions regarding this article, please contact CART at 562-401-6800 or visit [www.rancho.org/cart](http://www.rancho.org/cart).



## Honor Someone You Love

### Community of Hope Tribute Funds

By making a gift to the Community of Hope Tribute Giving Program at the Greater Los Angeles Chapter, you acknowledge someone who is important to you, and support the free programs and services provided by the Chapter every day.

#### Celebrate

A Gift In Celebration is a unique way to tell family, friends, or colleagues that you are thinking of them.

#### Honor

A Gift In Honor can acknowledge the work of someone who deserves special recognition for his or her compassion and commitment. The Chapter will notify the individual(s) being honored with a letter acknowledging your donation.

#### Remember

A Gift In Memory is a meaningful way to remember a loved one. The Chapter will acknowledge all donations given in memory with a letter to the next of kin that includes an expression of sympathy.

**For more information or to make your tribute gift, please contact us at (818) 865-8067, visit our website at [www.alsala.org](http://www.alsala.org), fax us at (818) 865-8066, or mail your contribution to:**

**The ALS Association Greater Los Angeles Chapter  
P.O. Box 565  
Agoura Hills, CA 91376-0565**

**Honor someone you love today.**

## Support Groups

No reservations required and no fee to attend. For more information or for directions, call **Patient Services at (818) 865-8067, ext. 234.**

#### Long Beach

Group Leader: Melissa Marie Pealer (916) 716-0829  
3rd Friday of each month / Noon - 1:30 p.m.  
Family Health Education Center  
3820 Cherry Avenue, Long Beach

#### West Los Angeles

Group Leader: Linda O'Connor, L.C.S.W. (310) 423-1065  
2nd Saturday of each month / 1:00 p.m. - 2:30 p.m.  
West L.A. Service Center, VA Hospital Grounds Room B  
11301 Wilshire Blvd. (Enter through main VA Hospital.)

#### San Bernardino County

Group Leader: Julie Lacanlale, C.M.A. (909) 558-2128  
3rd Saturday Every Month / 1:00 p.m. - 2:30 p.m.  
At The Carpenter's House Church  
13489 Arrow Route, Fontana

#### Ventura County

Group Leader: Deborah Saier (805) 551-8622  
4th Saturday Every Month / 1:00 p.m. - 2:30 p.m.  
At City of Westlake Village Community Room  
31200 Oak Crest Drive, Westlake Village

#### Loma Linda

Group Leader: Woody Totten, M. Div. (909) 797-4213  
3rd Thursday Every Month / 10:30 a.m. - Noon  
At Loma Linda University, Neurology  
11370 Anderson Street, Room 3675

#### Pasadena

Group Leader: Janet Simms, R.N. (323) 222-1808  
3rd Saturday Every Month / 2:00 p.m. - 3:30 p.m.  
At Lamanda Park Library  
140 South Altadena Drive, Pasadena

#### Bakersfield

Group Leader: Kristan Warren (818) 865-8067 x304  
2nd Saturday Every Month / 1:00 p.m. - 2:30 p.m.  
At HEALTHSOUTH  
5001 Commerce Drive, Bakersfield

#### Santa Clarita Valley

Group Leader: Janet Simms (323) 222-1808  
1st Saturday Every Month / 1:00 p.m. - 2:30 p.m.  
At United Methodist Church  
25718 McBean Parkway, Valencia

#### Riverside County

Group Leader: Griselda Perez (951) 259-9222  
1st Tuesday of the month / 10:30 a.m. - Noon  
At Portola Community Center  
45480 Portola Avenue, Palm Desert

#### Spanish Speaking Group

Group Leader: Martha Mowatt (562) 889-9452, ext. 305  
El Tercer Sabado en enero, abril, julio, y octubre  
A la Biblioteca Leland R. Weaver  
4035 Tweedy Boulevard, South Gate  
Comuniquese con Martha si tiene alguna pregunta.



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Ask your Human Resources department if your company has an employee giving campaign. Many companies have workplace giving programs like United Way, Community Health Charities of California (program number 6521), or the Combined Federal Giving Campaign.

Employee giving campaigns make it easy to contribute through payroll deduction.

Donors can select the specific charity they want to support. Be sure to include our tax identification number: **95-4163338**.

For more information on employee giving programs, please contact the Chapter at **(818) 865-8067**.

## One Woman's Labor of Love

Alicia Elizalde enlists 75 local businesses and attracts up to 200 people to attend the fundraiser she organized at Pepe's Restaurant in Canyon Lake to fight the disease that took her mother.

By James Klein, Editor

How is a fundraiser born? Alicia Elizalde claims a radio DJ gave her the idea. "It started because in 1993 my mother died of ALS, and one morning I heard Mark on *Mark & Kim*, KOST Radio," Elizalde recalls. "He was talking about his brother Ernie having ALS and how he had a basketball



Alicia Elizalde, her granddaughter Madyson Stickels, Marty Gibson with a commemorative plaque, and the Chapter's Director of Special Events, Giovanna D'Angelo (l to r)

fundraiser because Ernie liked playing basketball...and I said, well, if he can have a fundraiser, so can I."

Alicia approached Marty Gibson, the owner of Pepe's Restaurant in Canyon Lake, California, and asked if she could hold the fundraiser at Pepe's, offering to buy chips, guacamole and salsa for the crowd. "And he says, 'Well, no, Alicia.' And I thought, uh-oh. Then he says, 'If you're going to ask for money, they're going to want food. So don't worry about it, I'll get you the food.'"

Marty Gibson's generous offer jump-started Alicia's efforts to bring in other area merchants. "I started running around to the markets and restaurants and any place I could think of to collect gift certificates."

That was five years ago. The Pepe's fundraiser has been raising money every year since then to fight ALS. Alicia charges five dollars to attend, and Marty Gibson donates a wonderful all-you-can-eat spread and a karaoke system. In ad-



PALS Steve Heindorn at the Pepe's Fundraiser with three Laker Girls

dition, this year's event, which took place September 6, featured Thunder, a large, blue costume maskot dog for the Lake Elsinore Storm baseball team, who entertains the crowd, and an appearance by three of the Laker Girls.

Alicia plans to hold another fundraiser at Pepe's next year. "We've just got to find a cure. That's all there is to it. And I'm going to keep on going until I can't keep on going because watching my mother die was hell."

## Neiman Marcus Topanga Gala Raises over \$37,000 for Chapter

The Gala on September 4, 2008 celebrating the opening of Neiman Marcus' Topanga store brought in \$37,275 for The ALS Association Greater Los Angeles Chapter, and also benefitted three other local charities. Neiman Marcus Topanga officially opened its doors on September 5.

"Neiman Marcus is thrilled to open our 40th store in Topanga, California. As importantly, we are honored to be associated with four very special non-profit organizations with meaningful ties to the greater Los Angeles community," said Karen Katz, Neiman Marcus President and CEO. "Throughout our company's history, we have worked to be an involved and caring corporate citizen, and we look forward to supporting the community that supports the store!"

The ALS Association Greater Los Angeles Chapter, Grossman Burn Foundation, The MOCA Projects Council of The Museum of Contemporary Art, Los Angeles (MOCA), and the New West Symphony received money raised at the event.

A Neiman Marcus Fashion Show was held May 28, 2008 as a kick-off event for the Topanga Grand Opening Gala.



Neiman Marcus Public Relations Manager Jennifer Hudson, General Manager Bob Lugari, Greater Los Angeles Chapter Director of Special Events Giovanna D'Angelo, Chapter supporters Lynn and Howard Safenowitz, and Chapter CEO Fred Fisher (l to r)



# Paddling for Peacha with Sharks

Despite fatigue, Mako sharks and diesel spills, Tom Horton raises over \$33,000 for the Chapter in the Catalina Classic Paddleboard Race on August 24, 2008. Tom's mother, Peacha, passed away from ALS in 2005.

By James Klein, Editor

For the second year in a row, Tom Horton contributed to the fight against Lou Gehrig's Disease by "Paddling for Peacha," as he calls the effort, in the Catalina Classic Paddleboard Race, a 32-mile marathon Tom has competed in four times from the Catalina Isthmus to the Manhattan Beach Pier.

Tom describes how participating in the event and raising money to fight ALS helped him resolve emotions that arose during his mother's illness: "Well for me, especially this year, I had the sense that it was the first time I actually did something for her, even though it was in honor of her posthumously....it was such a horrible feeling watching someone you love so much deal with this disease, and there is nothing really you could do for her, other than stand by their side.

"So I don't know if it's a sense of guilt, I think there is a little bit of that, a sense of guilt and just despair and frustration, and anger. And the fundraising part, especially this year because it was such a successful fundraiser...whatever that burden was just was lifted from my shoulders..."

A Regional Account Director for Genzyme's Genetics division, Tom raised \$26,367 from friends, family, coworkers and other contributors, and received an additional \$7,000 from Genzyme's G.I.V.E. (Genzyme Invests in Volunteer Efforts) program, which provides grants of between \$1,000 and \$10,000 to charitable organizations for which employees volunteer.

Now in its 33rd year, the Catalina Classic is considered the premier paddleboard race in the world. Tom finished in the middle of the field of 96 paddlers, in a time six hours and 36 minutes, demolishing his previous year's time of eight hours and 13 minutes. At 49 years of age, his performance among world-class paddleboarders is remarkable.

"Out of the four years, this year was

my best year," Tom reports.

It was also his best year for fundraising. "I've got to acknowledge Genzyme," says Horton. "They really encourage volunteerism with the employees...I think a lot of people contributed more than they would have because of the additional money that Genzyme contributed."

Jerry Conway, Genzyme's Vice President, Managed Care, supported Tom Horton as his "ocean escort" during the race. In the September 2008 issue of Genzyme's genTymes magazine, Conway recalls how from a nearby boat he held a 12-foot pool-skimmer pole with liquid food and drinks for Horton as he paddled, "...witnessing him paddle (by hand, no oars or standard paddles here) his skinny fiberglass board across 32 miles of open Pacific, over Mako sharks and diesel spills, around whales and dolphins ..."

Conway also writes about Horton's fatigue before the race: "Despite having made the error of paddling 7-8 miles in open water to access an island ATM and fishing with us in the sun all day the day before the race (prevailing wisdom dictates you do nothing the day before this Ironman of Paddle Boarding), he got no sleep and set forth cheerily at 5:30 AM on his way towards the starting line."

"It was mayhem," continues Conway. "Escort boats and paddlers all over the place, squid jumping from the surf, sailboats almost running over Tom several times..."

Despite sharks, exhaustion, wild squid and errant sailors, Horton is looking forward to participating in the race next year.

*Contributions can be made online at [www.alsala.org](http://www.alsala.org), or by mail simply write "Paddling for Peacha" in the memo portion of your check to: The ALS Association Greater Los Angeles Chapter, P.O. Box 565, Agoura Hills, CA 91376-0565.*



Tom Horton with his paddleboard and checks representing over \$33,000 in funds raised from his contributors and Genzyme

## Genzyme's ALS Research

Genzyme's innovative viral approach to delivering neurotrophic factors may make all the difference, according to Senior Scientist James C. Dodge.

"We've seen neurotrophic factors may be beneficial for ALS, however, when they were tested in clinical trials, they failed to provide any form of benefit," says Dodge. "We thought the main reason for this was that they were inadequately delivered to the central nervous system. So we've come up with a couple of different ways for delivering neurotrophic factors, namely insulin-like growth factor-1...and we have tested these delivery strategies in ALS mice and shown that we can provide benefit.

"What we need to do now is test it in a large brain to see if we get the same biodistribution of the trophic factor..."

Dodge says Genzyme is planning to study the system in non-human primates. If the research is successful, it could lead to testing on human ALS patients.

# Cops Running for Charity and Memories of Papa

Seven Sheriff's Deputies known as *Cops Running for Charity* ran 35 miles in Iceland on July 7, 2008 to raise money for charities, including The ALS Association Greater Los Angeles Chapter, which received \$8,400.

By Joe Devorick

I ran an ultra-marathon this summer with a group of co-workers as a charity event. We are all Deputies with the Ventura County Sheriff's Department. I was surprised by how many friends and family members asked me "Why?" when I told them of my plans. To be truthful, I ponder the same question many times.

A few years ago, my father, Frank Devorick, retired from the Oxnard Police Department after 31 years of service. He had talked about his retirement for several years. His plans included fishing trips, travel with my Mother, and a new Cadillac. For some reason, he felt compelled to drive his 20 year-old pickup until he finished the job.

Fate had another plan for Frank. He was diagnosed with ALS just three months after his retirement. He never did buy that Cadillac. He and my mother opted for a minivan; wheelchairs tend to fit better into vans. Unfortunately, my father's ALS moved quickly and he passed away a little over two years after his diagnosis.

My family had always been very close and my father was the glue, although we didn't know how much until after his death. ALS was hard on my entire family. Two of my sisters went through a divorce, I asked for a job transfer from a unit I thought I would never leave, and my mother had a hard time going from caregiver back to a normal life. We all began wondering why this happened to my father, and to us.

Things slowly stabilized and in 2005, my wonderful wife Sandy talked me into participating in the Ventura County *Walk to Defeat ALS™* event. All of Frank's grandkids called him Papa, so we named our team "Memories of Papa".

About a year later, I bumped into Randy Pentis in a hallway at work. I hadn't talked with Randy in sometime and we did some quick catching up. Randy



Five members of *Cops Running for Charity* with Giovanna D'Angelo, the Chapter's Director of Special Events

was running marathons and competing in triathlons as charity events to raise money for juvenile diabetes. Randy's son, Dominic, was diagnosed with juvenile diabetes and he was looking for a positive way to give back for all the help he had received. Randy explained that he had started a group called Cops Running for Charity (CRFC).

Randy also asked about my family and how they were coping with this significant loss. Randy is from Italy, where family means everything. I explained that ALS had been hard on everyone. As we parted, Randy told me if I completed the Wildflower Triathlon then he would donate money to ALS. I accepted the challenge. After completing the triathlon, Randy donated \$500. He then said that if I completed a longer triathlon the next year, CRFC would donate \$1,000 to The ALS Association Greater Los Angeles Chapter. Both happened.

Meanwhile, Randy's group of runners, all members of the Ventura County Sheriff's Department, continued to grow. It now included Captains Tim Hagel and Dave Kenney, Sergeants Frank Underlin and Paul Higgason, and Senior Deputy Peter Frank. CRFC's list of charities was also growing, and the number of sponsors as well, which included sev-

eral local businesses and citizens.

CRFC had completed marathons in Death Valley, New York and Chicago. They even completed a 120-kilometer stage race in the Sahara Desert, and the Great Wall of China Marathon in 2007.

So in July, I officially joined Cops Running for Charity. We ran an Ultra-Marathon in the backcountry of Iceland. We ran along glaciers, active volcanoes, through rivers and across ice fields. In the end, CRFC raised over \$33,000 for charity. All of their donations go directly to charities. On October 16, 2008, CRFC presented a check to The ALS Association Greater Los Angeles Chapter.

CRFC's next challenge will take place in the Patagonia region of South America. We plan on running a marathon, Fin Del Mundo, in the Southern part of Argentina in March 2009. We are also committed to raise \$5,000 for the fight against ALS.

Apparently, the question "Why?" is often asked of long distance runners. I think the answer for everyone is different and sometimes there is no answer. For me, at least at times, I felt it was a little self-serving even though I was running for charity. Then I heard this quote – The greatest gift you can give to yourself is, to give to something bigger than yourself.

I wish I could answer why ALS strikes, but I can't. I do know that with enough giving we can find the answer and defeat Lou Gehrig's disease. For those individuals and families now suffering through this terrible disease, you are in my prayers.

*Anyone wishing to make a donation to CRFC can please make checks payable to "CRFC" for the benefit of the Greater Los Angeles Chapter, and mail them to:*  
*Cops Running for Charity*  
*C/O Captain Randy Pentis*  
*2101 E. Olsen Road*  
*Thousand Oaks, Ca. 91360*  
*(FEIN 51-0571160 Non-Profit Tax Exempt 501-C Org.)*



### Reeve Foundation Grant Supports Patient Services

The Christopher and Dana Reeve Foundation has awarded an \$8,400 *Quality of Life Grant* to fund The ALS Association Greater Los Angeles Chapter's support groups and *Ask the Experts* seminars.

ALS patients have a choice of 10 Chapter support groups, currently held in Long Beach, West Los Angeles, Fontana, Westlake Village, Loma Linda, Pasadena, Bakersfield, Palm Desert, Valencia, and in South Gate for Spanish speakers (see page 8 for more information).

The Chapter's popular *Ask the Experts* seminars are held regularly to give patients, families and caregivers the chance to hear from and question leading authorities on a range of topics that are important to PALS.

The Reeve Foundation has awarded almost \$800,000 in *Quality of Life* grants to nearly 100 nonprofit organizations worldwide to improve opportunities, access, and day-to-day quality of life for families and individuals living with disabilities. More information can be found at [www.christopherreeve.org](http://www.christopherreeve.org).

### A Gift for Her Grandfather

Samantha (Sammy) Dorenfeld donated \$500 to the Chapter in honor of her grandfather, Irving Dorenfeld. The money came from gifts Sammy received for her Bat Mitzvah.

Sammy's older sister, Dylan, did the same last year, donating \$500 to the Chapter in honor of her grandfather for one of her Bat Mitzvah projects. Irving's wife, Cookie Dorenfeld, has supported the Chapter in many ways, including joining the delegation that met with California Senators last year to encourage legislation in support of ALS patients and their families.

The Chapter thanks Sammy, Dylan, and the entire Dorenfeld family for their generosity and support.



Irving, Samantha, and Cookie Dorenfeld

## Charitable IRA Rollover Benefit Restored

By James Klein, Editor

On October 3, 2008, the Emergency Economic Stabilization Act of 2008 (H.R. 1424) reactivated the IRA Charitable Rollover tax incentive for 2008 and 2009.

This means your gift to The ALS Association Greater Los Angeles Chapter can be made completely tax-free. Your generous, charitable donation will help us find a cure for Lou Gehrig's disease and help patients and families who are bravely living with ALS today.

The new law enables anyone over age 70 ½ to donate funds to a public charity directly from their IRA or Roth IRA. The legislation gives you a special opportunity to make a charitable gift directly from your IRA even if you take the standard IRS income tax deduction or have maximized your giving for the year.

The Charitable IRA Rollover provision allows older Americans to make direct gifts to charity up to \$100,000 each year in 2008 and 2009. Only contributions made between January 1, 2008 and December 31, 2008 are eligible for the added benefit this year.

If you are at least age 70 ½ by the time you make your direct gift, it will count as part (or all) of your required distribution without your having to include the direct distribution in your taxable income.

Congress intends the legislation to benefit donors of all incomes, even those who do not itemize their tax deductions and might not otherwise receive any tax benefit for their contributions.

The kinds of retirement accounts you can use for your IRA Rollover include Individual Retirement Accounts or Roth IRAs. Donations from 403(b) plans, 401(k) plans, pension and other retirement plans are not eligible.

IRA Charitable Rollover funds must be donated to qualifying nonprofits that are public charities. Contributions to supporting organizations, donor-advised funds, and most private foundations do not qualify for the tax-free treatment. Check with your tax advisor to be sure.

An IRA Rollover gift must be an outright donation in order to qualify for tax-

free treatment. The charity that receives the gift must provide you with a receipt.

Your IRA Custodian or Administrator can arrange for this gift to be made directly from your IRA. If you take a distribution and then donate the funds, they will be considered taxable income.

Contact your Custodian or Administrator as soon as possible in order to complete the gift before the end of the year. Please instruct them to make a direct IRA Charitable Rollover donation to the Greater Los Angeles Chapter.

If you prefer to make your gift in another way, please consider designating the Chapter as the beneficiary of your IRA, or ask your advisor about other ways to benefit the Chapter in the future. If you create a future gift, please let us know. We would be delighted to honor your thoughtfulness and generosity now.

*For more information on ways to help the Chapter, please call us at (818) 865-8067. This information is not intended as tax or legal advice. Please contact your accountant or tax advisor.*

## Save The Dates!

**Tuesday, February 10, 2009**  
**The ALS Association Greater Los Angeles Chapter Annual Meeting**  
Skirball Cultural Center  
Los Angeles, California

**Sunday, May 10 - Tuesday, May 12, 2009**  
**National ALS Advocacy Day and Public Policy Conference**  
Washington, D.C.

**Sunday, April 26, 2009**  
**San Bernardino/Riverside County Walk to Defeat ALS™**  
Redlands, California

**Sunday, May 3, 2009**  
**Ventura/Santa Barbara County Walk to Defeat ALS™**  
Plaza Park  
Ventura, California

**Thursday, July 23 - Sunday, July 26, 2009**  
**Strike Out Lou Gehrig's Disease All Star Baseball Tournament**  
Thousand Oaks, California

**For more information, please call (818) 865-8067 or visit [www.alsala.org](http://www.alsala.org).**

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### Volume 4, 2008

We wish to express our sincere gratitude to everyone who has contributed articles, written letters, or provided information for this issue.

We make every effort to ensure this newsletter is accurate. If there are misspellings or other errors, please accept our apologies and notify us immediately.

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Information provided by The ALS Association Greater Los Angeles Chapter does not constitute therapeutic recommendations or prescriptions. All information and decisions should be discussed with a physician.



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