VISION

CREATING A WORLD WITHOUT ALS

ALS Association®
Fighting Lou Gehrig's Disease

Volume 7 Fall 2012 alsa.org

Lawrence R. Barnett's

Legacy of Hope and Challenge to Cure ALS

September 13, 1913 – June 11, 2012

> *"It's my personal mission to stamp out ALS"*

By Greg Cash

Entertainment industry executive, philanthropist, devoted husband and loving father, Lawrence R. Barnett touched thousands of lives over the course of his time on this earth, which was just a year and three months short of a century.

"I've always felt like I needed to help humanity as much as I can. And we are so happy to be able to give back to society," Barnett said also speaking on behalf his lovely wife of 53 years, Isabel Bigley Barnett, who was a Tony Award-winning actress recognized for her role in the original Broadway production of "Guys and Dolls." Isabel Barnett passed away in 2006.

Barnett led the effort to establish The ALS Association in 1985, became the first Chair of the Board of Trustees and served on various committees, provided leadership and frequently funding important initiatives. One research project he supported eventually isolated the first ALS gene, SOD1, in 1993. This discovery led to the development of the first ALS animal model, which was the catalyst for thousands of scientists, worldwide, to enter the ALS field of research.

When he received news of the discovery, Barnett was elated and said, "This breakthrough brings us one step closer to finding the cause for the disease." However, to ensure that a steady stream of young minds would continue to study ALS, Barnett also provided funding for The Association's inaugural ALS Post-Doctoral Fellowship in 2003.

Please turn to page 6

Corporate Partners Provide Vital Link to Defeat ALS

By Liz Hall

When we think about the fight against ALS, we often envision our front-line warriors—brave people with ALS, devoted caregivers, caring physicians and gifted researchers. However, there is another group of champions who deserve recognition for their support in the quest to create a world without ALS: The ALS Association corporate partners.

This year, hundreds of companies, large and small, will join The ALS Association in our fight through financial contributions, volunteerism and advocacy. Among these champions are Quantum Rehab and Pride Mobility, which pledged more than $250,000 this year in support of the Walk to Defeat ALS,® and donated power wheelchairs and mobility equipment to local ALS Association chapter loan closets to support people across the nation living with ALS.

QUANTUM®
LIFE BEYOND LIMITS™

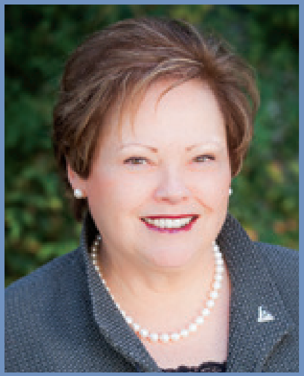
Pride®
Mobility Products Corp.
— LIVE YOUR BEST™ —

"Quantum Rehab and Pride Mobility Products Corporation are strongly committed to partnering with charities that work to

Please turn to page 2

Out of Sadness Comes Hope

Message from The ALS Association President and CEO **Jane H. Gilbert**



President and CEO
Jane H. Gilbert

This past June, the ALS community lost a great champion of our cause with the passing of Lawrence R. Barnett. Designated as the “Grandfather” of The ALS Association, he was among the dedicated people who charted The Association, and he served as its first Chair of the National Board of Trustees.

Through his leadership and love for humankind, he helped guide the fight against ALS and personally funded important research projects, which have brought us to perhaps the most exciting point in the history of ALS. With the recent discoveries of new ALS genes and disease mechanisms, we feel scientists are on the brink of finding meaningful ALS treatments. Some of the more promising areas of research include stem cells, biomarkers and the new diaphragm pacing system.

Even though Lawrence Barnett no longer walks among us, his spirit lives on in our hearts and his children and grandchildren, who are carrying his legacy forward as we work together to create a world without ALS.

VISION

Corporate Partners

Continued from page 1

support those impacted by ALS,” said Meghan Kutch, General Manager, Quantum Applications and Clinical Development. “We have long maintained a strong involvement in various walks, rides and other events on both the corporate and individual employee level to help raise funds to increase awareness and find a cure for ALS. We are a national partner and promote ALS awareness across the country.”

Quantum Rehab and Pride Mobility representatives will be at walks across the country this fall, so if you see one of them, please thank them for their support!

Sanofi, manufacturer of a Rilutek®—the only FDA-approved drug to treat symptoms of ALS—has been a long time donor and advocate of The ALS Association. This year, Sanofi made a commitment of $250,000 to support care services and educational initiatives. Its contribution will allow The Association to provide much needed training for care coordinators across the country and will help The Association develop and distribute educational materials for individual and families touched by ALS.

This summer, PostNet International added its voice to raise ALS awareness and dollars in support of The ALS Association. Its “pin up” campaign not only provided important funds to local chapters, but also spread the word about ALS in more than 225 communities across the country. Because of its support, thousands of people now have a better understanding of this disease.

Nationwide, companies like these are making ALS a priority. Because of their commitment, The ALS Association continues to provide vital services and lead the way in the search for effective treatments and a cure for ALS.

Good Advice
in Difficult Times

By Stephanie Dufner

Blogger Bo Stern explores life's small pleasures and major milestones in her blog "Bo Stern: The Difference of Day" (www.bostern.com). "I'll usually discuss the circumstances of life," explained the 46-year-old mother of four, who also works as a pastor and teacher at Westside Church in Bend, Oregon. "I'll sometimes blog about the frustrations of living with ALS or about the joys of a really good cupcake."

Stern has chronicled her dismay with Lou Gehrig's Disease since doctors diagnosed her husband, Steve Stern, with the disease in February 2011. She has discussed how ALS has impacted Steve's ability to perform everyday tasks like opening a jar of mayonnaise or changing light bulbs. Stern has also written about the camaraderie and strength she and her beloved experienced when they attended The ALS Association's National ALS Advocacy Day and Public Policy Conference in Washington, D.C., in May.

"The Difference of Day" has an estimated 1,000 followers. Stern admitted that she often recounts her family's dealings with Lou Gehrig's Disease in order to spread awareness in and beyond her community.

"The general public is so uninformed about the disease, and I am so passionate about helping them understand the reality of those who face it," said Stern.

Stern also related her elation when she connects with those intimately familiar with ALS. "My favorite moment is when a PALS or CALS reads my blog and tells me it gave words to what they are feeling," she said.

Undoubtedly, Stern's biggest fan is her spouse. Steve revealed how his wife's blog affects him on a physical and emotional level. "I love Bo's blog. Reading it is like falling in love with her all over again," he said. "The reality is that our lives are so connected that I feel her writing deep in my spirit and soul."

Bo Stern's book, *Beautiful Battlefields*, will be published in February 2013.

The Sterns at the 2012 National ALS Advocacy Day and Public Policy Conference in Washington, D.C.

Community Partners Fight Lou Gehrig's Disease

By Cathryn Savino

For more than half a century, Community Health Charities (CHC) has represented the most well-respected health charities in the country. It works to improve the lives of people affected by a disability or chronic disease by uniting caring donors in the workplace with the nation's most trusted health charities. The ALS Association is a proud member of CHC and is honored to continue the partnership for the 11th year.

The Combined Federal Campaign (CFC), an extension of CHC, is designed to unite federal employees with worthy causes and its campaign began September 1 and runs through December. If you are a federal employee, watch for announcements on how you can support The ALS Association through workplace giving.

Private sector employees can visit www.alsa.org to learn how your company can get involved in the workplace giving campaign locally! As a caring donor and supporter of The ALS Association, your funds through workplace giving support our international research program, local chapters providing care services to people with ALS, and Public Policy efforts providing a voice to those who can no longer speak.

THE CARE CONNECTION PROGRAM

Taking the Guesswork Out of Helping a Friend

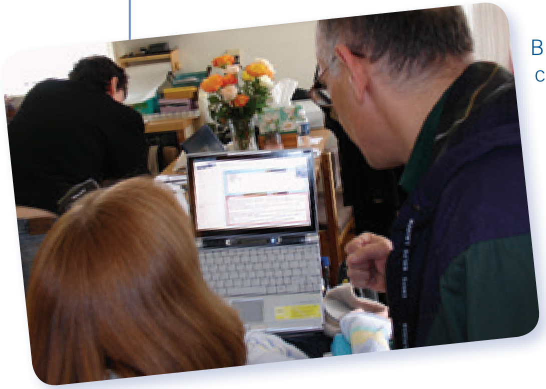
By Cynthia Knoche

The ALS Association has launched its 2012 Care Connection Program. Those diagnosed with ALS, or caring for someone diagnosed with ALS, fully understand the challenges of daily life with a progressive neuromuscular illness. Family and friends are also often aware of the many challenges, but simply don't know how, when or where to help. The ALS Association's Care Connection Program literally "takes the guesswork out of helping a friend."

Today's Care Connection Program provides a succinct, educational and operational guide to maximize and fulfill the unmet needs of families with the kindness and efforts of friends in the community. The user-friendly guide provides a framework from which ALS Association chapter staff educate a family-selected Care Connection Coordinator on how to organize a person or family's community of friends into an effective care and support team. The huge benefit of this program is that it provides a simple avenue for a family living with Lou Gehrig's Disease to indicate what their needs are, while at the same time allowing family and friends to provide support and assist in meeting identified needs according to their schedules.

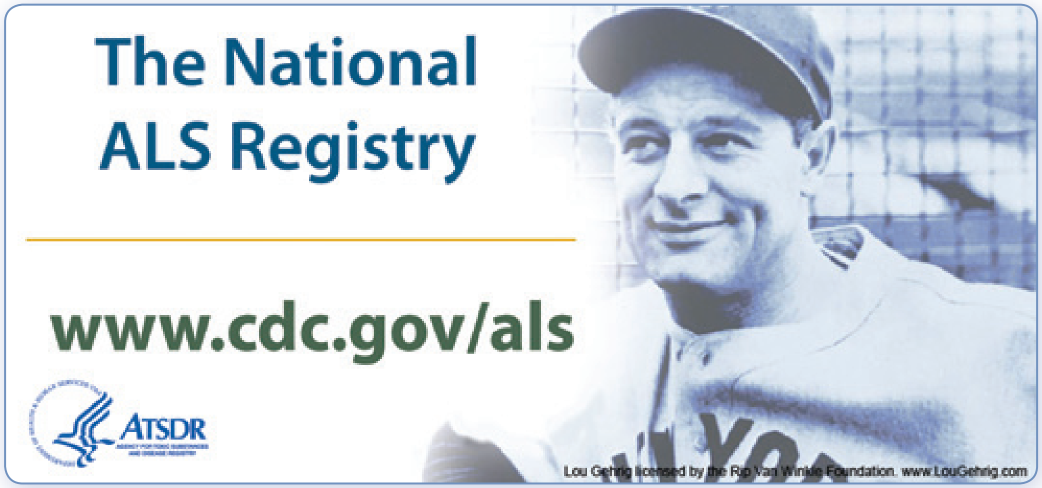
Caregivers' mounting task list often leaves little time to simplify their hectic lives, experience peace of mind or even enjoy a bit of time for themselves. Utilizing a private web-based calendar, Family Care Connection Coordinators can list the unmet needs of a family, such as weekend boxed meal delivery, dog walking or fall leaves raking activities. Volunteer members of the family's Care Connection community simply log on to view the calendar and indicate which needs they may be able to address.

The Care Services Department extends its appreciation to Sanofi US for its support of the educational endeavors of The ALS Association.



Build an online community for care

Care Connection helps the entire family



People with ALS Making a Difference in ALS Research

By Patrick Wildman

Every day, people with ALS are making a difference in the fight to end the disease. One way is through the National ALS Registry. This critical research program is collecting vital information about the disease—directly from the people living with it. This information will help doctors and researchers learn more as they work to find the cause, treatment and cure.

Nobody knows what causes ALS or how it can be prevented. We also do not know how many people are living with ALS in the United States. To help find answers to these questions, in 2008 Congress passed legislation to create the National ALS Registry. The Agency for Toxic Substances and Disease Registry, a sister agency to the Centers for Disease Control and Prevention, created and maintains the Registry.

Persons with ALS (PALS) may enroll in the Registry and provide important information about their lives. This information can help researchers solve the mysteries of ALS. Registered PALS may provide information on possible risk factors leading to the disease. The information provided by PALS may include who they are, their family history, where they have lived or worked, and how they are coping with the disease. Researchers will use Registry information to measure the true impact of ALS on the nation by determining how many people have the disease.

The Registry is helping to advance ALS research. But it can also be an important resource for people with ALS and their families. Tools are available on the Registry website to assist PALS in locating ALS services in their community. The Registry also has developed a clinical research notification system to inform PALS about new clinical trials in which they may be eligible to participate.

The National ALS Registry can be a tremendous resource to advance the fight against the disease. The participation of persons living with ALS is critical. And it is one important way PALS can make a difference in ALS research. To learn more or to enroll, go to www.cdc.gov/als.

Walk to Defeat ALS®
The ALS Association

Why We Walk

By Cathryn Savino

Stephen Smith of Columbia Falls, Montana, is no stranger to tough climbs. He has organized and led five expeditions to the top of the more than 14,000-foot-high Mt. Rainier and for his sixth time, he is doing it in honor of his friend Dr. Erik Schroeder, who was recently diagnosed with ALS. When Smith heard of the Missoula Walk to Defeat ALS,® he formed a team in honor of his friend and took his fundraising efforts vertical.


Stephen Smith

"Rainier is not a mountain that is conquered," Smith said. "It is probably similar with the quest to find a cure for ALS; careful planning, research and decision making are required, all of which cost money."

This is why Smith has taken to The Mountain in hopes of raising $10,000 for Dr. Erik Shroeder and the Missoula Walk to Defeat ALS.® He knows it will be challenging, but he is in it for the long haul.

Rex Riessen was 47 years old when he died from Lou Gehrig's Disease in 2008.


Rex Riessen

"I walk, quite simply, for Rex. He was my brother-in-law, diagnosed in 2006, just a few days before his birthday," said Sarah Peel Helgeson, Central Indiana Walk to Defeat ALS® Co-Chair and ALS Association Indiana Chapter Board Member.

Helgeson wants her sister's family—Rex's children and grandchildren—as well as other families fighting ALS, to know that there are people in the world who continue the battle to bring visibility and urgency to the cause. Participating in The ALS Association's Walk is a great way to show you care.

For more information visit www.walktodefeatals.org

New Law Aims to Speed Access to Treatments

By Patrick Wildman

The ALS Association scored an important victory in Washington, D.C., in late June 2012 as Congress passed the Prescription Drug User Fee Act (PDUFA), legislation that includes a number of vital reforms and resources that will help to speed access to new treatments for people with ALS.

The ALS Association has strongly supported PDUFA, having worked with Congress, FDA and others for more than a year to expedite its enactment. These efforts included developing advertisements featuring a person with ALS, which ran in Capitol Hill publications advocating for PDUFA (http://bit.ly/Qfo6kx).
The bill will:

- Improve and strengthen the FDA's Fast Track and Accelerated Approval processes to speed the approval of drugs to treat ALS and other serious and life threatening diseases;
- Provide the FDA with the flexibility to approve new treatments quicker by utilizing tools such as biomarkers and other surrogate endpoints, which can predict whether a treatment is effective much earlier in the drug development process;
- Help to ensure that ALS experts can participate on FDA advisory panels;
- Direct FDA to facilitate the development of breakthrough treatments by working more closely with companies and patients throughout the drug development and approval process;
- Reauthorize the Orphan Drug Grant Program, which provides funding to encourage the development of treatments for rare diseases like ALS;
- Require FDA to work closely with patient organizations, including those representing rare diseases, as it develops guidance and regulations; and
- Provide much needed funding and resources to the FDA, which will help the Agency to expedite drug approvals.

To learn how you can make a difference in the fight against ALS on Capitol Hill, become an ALS Advocate by visiting www.alsa.org/policy.

Barnett's Legacy

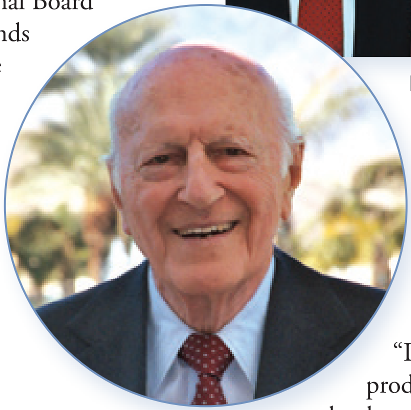
Continued from page 1

Lawrence, Isabel and son Larry Barnett

For his many years of leadership and support, Barnett became affectionately known as the "Grandfather" of The ALS Association, a distinction of which he was especially proud.

"Every organization has a George Washington, and Larry Barnett was the George Washington of The ALS Association," said current ALS Association National Board of Trustees Chair Jay Daugherty. "Thousands upon thousands of persons with ALS have benefited from Larry's wisdom, guidance and generosity."

As the patriarch of the Barnett family, he instilled his children and grandchildren with the value of philanthropy, in particular for the ALS cause. Barnett said, "Every patient makes an impression on you. When you meet a person with ALS, you keep asking yourself, 'What can I do to help this person?'"



One of Barnett's six children, Larry Barnett, has taken on the ALS cause and is serving on National Board of Trustees of The ALS Association, providing leadership and support, while carrying on the legacy of his father. "I am proud to continue my family's legacy of support," said the younger Barnett. "I want to do what I can to help find a cure and put an end to the terrible suffering caused by this disease."

In addition, Larry Barnett's teenage son, Beau, represents a third generation of the Barnett family to enter the fight against ALS by first spending a summer vacation volunteering at the national office of The Association. Last year, Beau Barnett turned a mountain climbing trek to the summit of Kilimanjaro into an ALS fundraising event.

"Lawrence R. Barnett lived a full and productive life, and we are grateful that he devoted a major portion of it to the ALS community," said ALS Association President and CEO Jane H. Gilbert. "We are also delighted, and ever so thankful, to have Larry and Beau following in his footsteps."

Speaking on behalf of The ALS Association at a memorial service held June 15, Robert Abendroth, close friend of Barnett and former ALS Association National Trustee, said, "Larry's passion for a cure for ALS will be missed. But his genuine philanthropic spirit cannot be erased. There will be others inspired by him to carry on."

Barnett family attending ALS Association event to honor Lawrence R. Barnett

Decades of *Love*—and a Gift of *Hope*

By Katie Sweeney

Don Mills has many reasons for supporting The ALS Association. His wife of 42 years, Edna Mills, died of ALS in 2000. Decades earlier, Edna's father and uncle also died of the disease.

Today, Don has yet another reason to support The Association: the future health of his three adult children.

"I'm particularly interested in research that's focused on the familial aspect of ALS, because it seems like there's a definite link in our family," said Mills, 79, who recently established a charitable gift annuity for The ALS Association to support ALS research. "My kids might be at risk."

Don and Edna's life together began in 1957, when they met in the then-quiet seaside town of Ventura, California. Edna was a legal secretary, and Don had graduated with an architectural engineering degree from California State Polytechnic University, San Luis Obispo. They met in the church choir and were quickly smitten.

They married a year later and settled in Ventura. Don began what would be a 43-year career in civil engineering, designing water supply facilities throughout Southern California. Meanwhile, they started a family, and Edna stayed home to raise their children: Colleen, David and Carol.

"She was energetic, enthusiastic, caring and loving," Mills continued. "She had lots of friends, so she was our social secretary, too!" he added, laughing.

Edna also was a committed volunteer. Among other activities, she spent three decades volunteering for the Ventura County Fair, served on the Ventura Parks and Recreation Commission for 12 years, helped update the city's charter, was active in raising funds to renovate the city's pier and was named "Citizen of the Year" by the chamber of commerce.

The first sign of illness appeared in May 1999, when she began having trouble lifting the front of her foot, a condition called "drop foot." A month later, Edna was diagnosed with ALS.

Her disease progressed rapidly, but she remained committed to her volunteer work, continuing to serve on the Parks and Recreation Commission and attending the dedication ceremony for the Ventura Pier's new terminus, which was named "Mills' End" in the couple's honor.

Just five days after that ceremony, on April 5, 2000, Edna passed away peacefully at home after a 10-month battle with ALS. She was 63.

Don and Edna Mills

"I feel fortunate I was able to care for her," said Mills. "We made every day count."

Today, Mills stays busy as a volunteer, using his engineering skills to assist with rehabilitation projects at his church and Channel Islands National Park. He also has three grandsons in college.

He and Edna began supporting The ALS Association in the early 1990s, and Don has continued that support. Recently, when a CD matured and his bank offered a minuscule interest rate, he used the funds for a charitable gift annuity, providing him with an attractive payment rate and substantial annual income that is guaranteed for his life.

"The ALS Association is at the forefront of ALS research, and it's so important to support this effort," he explained. "Little by little, the knowledge is growing. That's what gives me hope for the future."

Get a Tax Deduction and Retirement Security with an ALS Association Charitable Gift Annuity!

Current Payments and Payment Rates

Here are a few payment rates and payment amounts based on a donation to the ALS Association of $20,000 and one beneficiary. Contact us for your exact payment amount, based on your age and number of beneficiaries.

GIFT ANNUITY PAYMENT RATES

If your age is	60	70	75	80	85
Your payment will be	4.4%	5.1%	5.8%	6.8%	7.8%
Your annual payment will be	$880	$1,020	$1,160	$1,360	$1,560

** These payments are based on a donation of $20,000, one beneficiary and rates effective July 1, 2012. Rates subject to change.*

We recommend you seek the advice of an estate and/or tax professional in conncetion with any gift.

Call 1-888-949-2577 or email giftplanning@alsa-national.org

West's artistic
impression of
New York Yankee
Lou Gehrig

ALS Association®
NATIONAL OFFICE
1275 K Street NW, Suite 1050
Washington, DC 20005
alsa.org

Dated Material

Non Profit Org.
U.S. Postage
PAID
Santa Clarita, CA
Permit No. 379

An Artistic Flair

By Stephanie Dufner

Elvis. John Wayne. Lou Gehrig. Richard Petty. These are a few of the larger-than-life personalities that artist Raymond West has placed on canvas since doctors diagnosed him with ALS in January 2011.

West, 60, began his love of art as a middle schooler, but ceased cultivating his creative skills when he started playing basketball in high school. Today, he has regained his artistic aptitude, which helps him cope with Lou Gehrig's Disease.

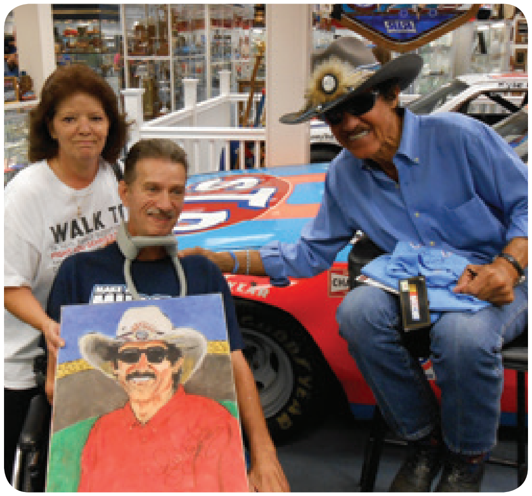
"Art brings peace to my mind," West said. "It helps me stay busy and makes me feel that I have a purpose in life."

Although ALS prevents West from holding a paintbrush, he has the ability to place a piece of chalk between two of his fingers. He runs the chalk over the canvas and blends the colors to create smooth pastel works of art.

"Ray exemplifies the description of someone who has chosen to 'live' with ALS," said Sue Humphries, LMSW, Director of Care Services at The ALS Association Jim "Catfish" Hunter Chapter. "He is an incredibly talented painter and is such an inspiration to everyone he meets."

Humphries works closely with West and his wife of 30 years, Sandra, at the chapter's monthly support group meetings in their hometown of Greensboro, North Carolina. Raymond and Sandra West also travelled to Washington, D.C., in May 2012 to the National ALS Advocacy Day and Public Policy Conference, where they shared their story with elected officials on Capitol Hill.

Sandra said her husband is now turning his talent toward another medium. "Ray plans to write and illustrate a children's book," she said. She revealed the book would help youngsters like their eight-year-old grandson, Braxton, understand ALS.



Sandra and Raymond West show West's painting of Richard Petty to the NASCAR superstar