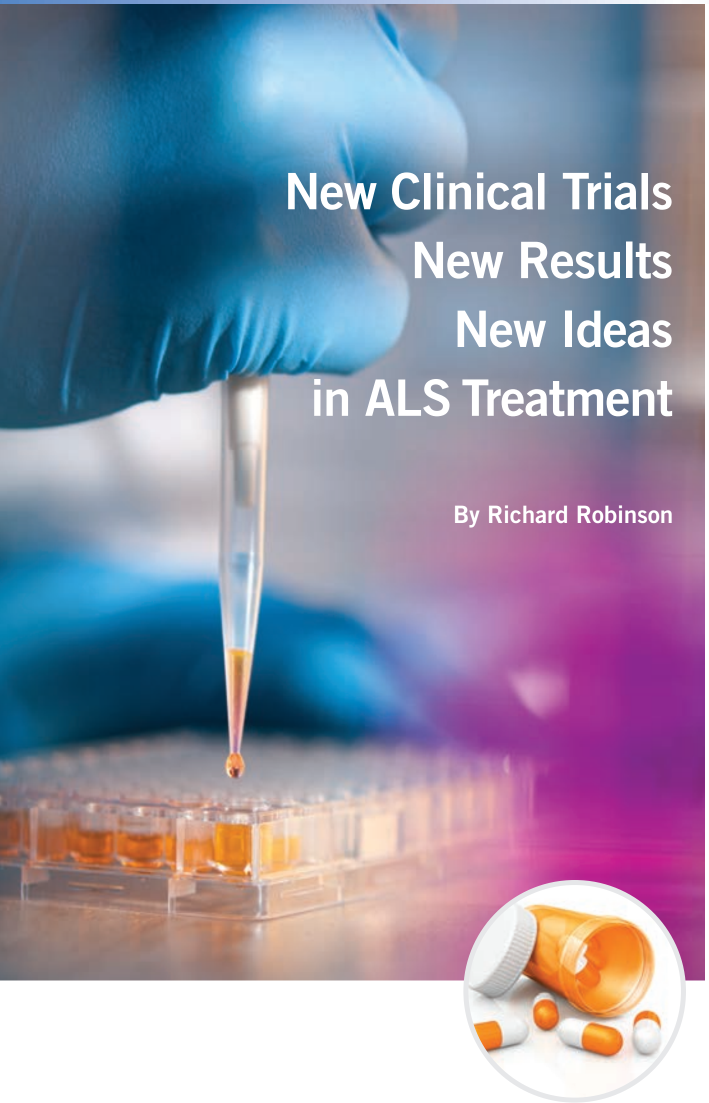
VISION

CREATING A WORLD WITHOUT ALS

ALS Association
Fighting Lou Gehrig's Disease

Volume 9 Fall 2013 alsa.org



New Clinical Trials New Results New Ideas in ALS Treatment

By Richard Robinson

More than three dozen ALS clinical trials are currently recruiting patients. These trials are testing interventions ranging from an approved cardiac drug to test its neuroprotective ability to botulinum toxin injections to reduce accumulation of excess saliva.

"This is an active time in ALS clinical research," according to ALS Association Chief Scientist Lucie Bruijn, Ph.D. "There are multiple trials testing multiple types of interventions, all with a focus on improving patient outcomes."

There have been disappointments in recent large clinical trials. A trial of dexpramipexole, which acts on cell energy producers called mitochondria, found there was no evidence of effect from either low- or high-dose drug compared to placebo. Similarly, there was no effect on disease progression from dosing with ceftriaxone, which increases the level of a cell membrane transporter for glutamate. Impaired glutamate transport is believed to contribute to the ALS disease process.

Despite these disappointments, researchers are more committed than ever to finding treatments to slow or halt the ALS disease process. Over a dozen biotech and large pharmaceutical companies are involved in therapy development programs. Some highlights of ongoing and upcoming trials include:

>Anti-SOD1 antisense. ISIS Pharmaceuticals has developed "antisense" molecules that bind to and cause the degradation of the messenger created from the mutant SOD1 gene. The mutant gene is responsible for about 10 percent of familial ALS. A trial of the antisense molecules was recently shown to be safe in ALS patients, setting the stage for development of a more efficient antisense molecule and resumption of clinical trials, likely to begin in 2014. The same company is in the early

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The ALS Association's Certified Center Cost Study

By Kim Maginnis

The multidisciplinary team approach to the treatment and management of patients with amyotrophic lateral sclerosis (ALS) has emerged as the preferred model of care with evidence for prolonged survival, improved quality of life and reduced hospital admissions. The Quality Standards Subcommittee of the American Academy of Neurology (AAN) developed evidence-based practice parameters for the care of people with ALS, which emphasized the need for multidisciplinary care and was first published in 1999 and later updated in 2009. Although multidisciplinary care is established as a desirable model for clinical practice for people with ALS, there are no published data available from the United States on the costs associated with this model for institutions adhering to the AAN Practice Parameters.

This review includes a three-month prospective, descriptive, multi-center study of the costs associated with care provided at a number of geographically diverse sites meeting the practice criteria for multidisciplinary ALS clinics and certified by The ALS Association. The study employs self-reported data collection tools evaluating costs associated

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Driving the Engine for Success

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

President and CEO
Jane H. Gilbert

In mid-August, we announced that The ALS Association is supporting 35 new research projects under our **T**ranslational **Re**search **A**dvancing **T**herapy (TREAT ALS™) program with $4.3 million in new research grants. Worldwide, The Association has funded a diverse portfolio of hundreds of research projects totaling more than $87 million.

The TREAT ALS program is supported through the generosity of individual donors, who share our passion to find effective treatments and ultimately a cure for ALS. In addition, The Association's nationwide network of chapters, which provide support and care services to people with ALS and their families, contribute to ALS research collectively and with the support of individuals in their communities across the United States.

The ALS Association TREAT ALS program is the driving force to identify the causes, develop new treatments and accelerate clinical trials for new therapies. Working directly with people with ALS, our focus includes, but certainly is not limited to, animal model systems, genetics and stem cells.

We are grateful to our many partnerships with governmental agencies, pharmaceutical and biotech industries, academia, global research community and other ALS organizations joining us in the fight against Lou Gehrig's Disease. Our combined efforts are demonstrating progress, but our battle is not yet won. Building on these successes, we will continue to work toward our ultimate quest of bringing an end to this devastating disease.

You may be aware that I have announced that I will be stepping down as President and CEO of The Association. I promised The Association's Board of Trustees that I would actively remain at my post until my successor is both identified and ready to assume leadership of The Association. My personal quest against ALS, however, will not stop. I am committed to this cause and will continue to serve The ALS Association and our ALS community until we find a treatment and cure.

New ALS Clinical Trials

Continued from page 1

stages of developing an antisense therapy against the messenger from the mutant C9orf72 gene, which accounts for about 40 percent of familial and six percent of sporadic ALS.

>Implantation of neural stem cells. Results from the initial NeuralStem trial indicate that implanting neural stem cells into the spinal cord is safe in ALS patients. That treatment will now be tested for signs of efficacy. The study is open for enrollment by invitation.

>Mexiletine. Mexiletine is an FDA-approved treatment for cardiac arrhythmia and neuropathic pain. Because it appears to protect neurons in certain traumatic conditions, researchers are now testing its ability to slow neuronal loss in ALS. Sites in multiple states across the United States are recruiting for this trial, which will compare two different doses of mexiletine and placebo.

Certified Center Cost Study

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with ALS care incurred by both the certified clinics and The Association. All data will be de-identified and no personal information will be disclosed.

One goal is to allow the ALS community and healthcare policy makers to have a better understanding of the breadth of services provided at ALS clinics. This data will also help identify opportunities to develop more cost-effective ways to provide multidisciplinary care and to reduce expenses or capture lost revenue. The study, analyses and journal articles are anticipated to be completed in the spring of 2014.

VISION

Tales of Hope, Strength and Grace

By Stephanie Dufner

Grandparents. Young fathers and mothers. Soldiers. These individuals, who come from divergent backgrounds from across the country, share this: They have ALS, and they or their loved ones disclosed personal stories about living with the disease for the 2013 ALS Awareness Month campaign in May.

"I hope for treatments"

For this year's campaign, The ALS Association invited members of the ALS community to tell the impact that the disease has had on their lives or the lives of their loved ones. The campaign, titled "*Create a world without ALS. Speak up now to give Hope*," invited people to tell their stories and discuss what they hope for in a world without ALS. Participants submitted either a photo, brief video or selected an image that read, "I hope for treatments"; "I hope for a cure"; "I hope for action"; or "I hope for awareness" to illustrate their statements. The Association has received more than 675 submissions.

"This year's campaign underscores the fact that ALS can affect anyone at any age or from any background," said ALS Association President and CEO Jane H. Gilbert. "The ALS Association is grateful that so many people participated in this campaign and chose to reveal how the disease has affected their lives."

One submission comes from a Pennsylvania nurse, who has been living with ALS for more than two years, and whose mother succumbed to the disease in 1991. The writer, Karen S., from Ottsville, advises for others with Lou Gehrig's Disease to join clinical trials. "The only way to find a cure or effective treatment for ALS is to put yourself out there," she said.

"I hope for a cure"

Social media served as another component of this campaign. The Association asked readers to post submissions on Twitter and "Like" them on Facebook for a contest. From each of The ALS Association market groups, the Facebook stories that received the most "Likes" received one of four motorized wheelchairs from Pride Mobility/Quantum Rehab. These Quantum Q6 Edge wheelchairs went to the winning chapters for their equipment loan closets. Chapters make these chairs available to people with ALS at no charge.

Contest winners included the following chapters, which are linked to their respective winning submittals: Texas Chapter (Market Group 1); Indiana Chapter (Market Group 2); South Carolina (Market Group 3); and Rhode Island (Market Group 4).

"The Quantum Q6 Edge donation to our chapters will certainly enhance independence and provide a better quality of life for those living with ALS," said Rhode Island Chapter Executive Director Nancy Feroldi. "There are not enough words to adequately express our profound gratitude for this gift to our chapter's equipment loan program."

"I hope for action"

"The Texas Chapter is grateful to Pride Mobility/Quantum Rehab for their donation of the power wheelchairs and to those we serve for sharing their stories of hope and courage that helped the Texas Chapter to win this amazing resource," said David Chayer, Executive Director of the Texas Chapter.

In addition to promoting the campaign on its website, The Association publicized it via a press release distributed to national media and in its monthly newsletters, *The Exchange* and *Vision Express*. The Association also asked participants to show their support during ALS Awareness Month by becoming an ALS advocate, following the organization on social media, or making a donation.

"I hope for awareness"

The ALS Association's Certified Center Program

The key premise of The ALS Association's Certified Center Program is to design, implement and monitor a national standard of best-practice care in the management of ALS. Since the program's inception, The ALS Association has certified 34 Certified Treatment Centers of Excellence throughout the country. These certifications are based on established requirements in terms of programs, professionals' skill sets, people living with ALS served, active involvement in ALS-related research, relationships with local Chapters and access to care.

Achieving certification through successful completion of the program's robust clinical and administrative reviews confirms to people living with ALS, family members, caregivers, national organizations, private and publicly-held companies, government institutions and other key stakeholders the validity and comprehensiveness of the Certified Treatment Center of Excellence's standards of quality and implementation of best practices. This certification process ensures that evidence-based care processes that are closely linked to positive outcomes are part of each individual's clinic experience.

In 2013, The ALS Association expanded and revised its Certified Center Program in order to be more inclusive and descriptive in the designation process. There are now two categories within the program: The ALS Association Certified Treatment Centers of Excellence and The ALS Association Recognized Treatment Centers. Each of these designations requires an initial review process and ongoing monitoring.

MISSED OPPORTUNITY

VA Benefits for Surviving Spouses

The connection between ALS and military service has been well established through the various studies conducted by Harvard, Department of Defense and Department of Veterans Affairs. Due to this connection, The ALS Association has fought to provide our military heroes with ALS the highest level of benefits available. In 2008, the Veterans Administration (VA) established a presumption of service connection for veterans diagnosed with ALS, qualifying veterans with ALS for the highest level of VA benefits regardless of where or when they served in the military.

While these benefits are critical to help veterans and their families battle ALS, many families do not realize that these benefits extend to them even after losing their loved one. The survivors' compensation is available regardless of whether a veteran was lost to ALS one year ago or decades ago.

The Association encourages veterans and their survivors to contact their local ALS Association chapter for assistance and guidance in obtaining VA benefits. Additionally, veteran service organizations, such as the Paralyzed Veterans of America, American Legion and Disabled American Veterans can help answer questions and assist with navigating the claims process. To learn more about how the vital benefits available to veterans and their survivors, please visit the Military Veterans section of our website at www.alsa.org/veterans.

VOCAL PRESENCE

A Veteran Reveals His Personal ALS Story to National Media

By Stephanie Dufner

One of the stories featured in this year's ALS Awareness Month campaign is from a retired Air Force Technical Sargent. David Masters, of Omaha, Neb., was just 32 years old when doctors diagnosed him with ALS. A self-described "health and fitness enthusiast," Masters began experiencing muscle weakness in his right arm during a deployment to Kuwait.

Military veterans are approximately twice as likely to be diagnosed with ALS as the general population for unknown reasons. The disease has transformed Masters' corporeal appearance. A photo from his deployment shows a man who represents the epitome of physical strength looking self-assured and ready for a challenge. Today, Masters appears thin yet resolute. He has lost the visible muscle mass in his arms that enabled his success as an amateur body builder.

David Masters

In spite of the disease's impact on his body, this young husband of Jodi and father of three remains a fighter, and he hopes for treatments and a cure for ALS. Masters spread ALS awareness by participating in a radio media tour in late May with several stations across the country, including the USA Radio Network. These stations interviewed him about how the disease has affected him. In addition, The Association highlighted Masters in a story about veterans and ALS, which appeared in more than 1,400 print and electronic national periodicals, including the *Los Angeles Times* and the *Houston Chronicle*.

Those familiar with Masters' story believe it has strongly impacted those who have heard or read it. Beckie Cooper, Executive Director of the Keith Worthington Chapter, which has worked closely with the Masters family, is one of them. "Since ALS is known and understood by few, it is crucial that we put a face on the disease," she said. "I have little doubt that David and Jodi's story was heard and will be remembered by thousands."

A Gift for Ginnie and Marian

By Katie Sweeney

Even now, at age 95, Henry Frankel still remembers that warm summer day back in 1941—the day that Virginia "Ginnie" Casey invited him to a friend's beach party on Lake Michigan.

At the time, both were working at Northern Trust Bank in Chicago. Ginnie was an IBM specialist, and Henry was her supervisor. He happily accepted her invitation.

"I was surprised because she normally was quite shy," Henry recalled. "That was the beginning of a growing friendship, which resulted in us being best friends forever."

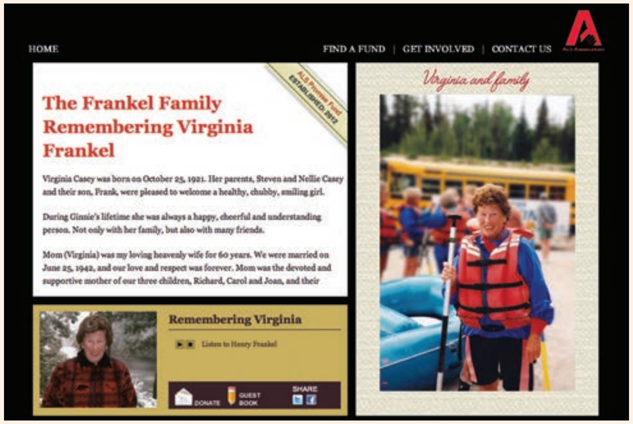
A year later, they were married—beginning a 60-year journey that included three children, six grandchildren, and today, nine great-grandchildren. Their journey together ended in 2003, when Ginnie, at the age of 81, died after a two-year battle with ALS.

Earlier this year, their son, Richard Frankel, and Richard's family—his wife, Lynn, and their three grown sons, Keith, Brian and Jeff—made a very meaningful gift to The ALS Association. Seventy-five percent of the gift will support ALS research; 25 percent will support patient care programs at The ALS Association's Orange County, Calif., Chapter.

The Frankels, who live in Corona del Mar, Calif., made the gift not only in memory of Richard's mother, but also in memory of Lynn's aunt, Marian Jindra, who died of ALS in 2009 at age 83. Marian was the mother of three and "like a second mother" to Lynn.

"Our family experienced the devastating impact of ALS not just once, but twice," Richard explained. "The ALS Association does a tremendous job of funding critical research and providing vital care services for patients and families. We felt strongly that we wanted to support them in both these efforts in the fight against ALS."

Virginia "Ginnie" and Henry Frankel



The Frankel Family Remembering Virginia Frankel

Virginia Casey was born on October 25, 1921. Her parents, Steven and Nellie Casey and their son, Frank, were pleased to welcome a healthy, chubby, smiling girl.

During Ginnie's lifetime she was always a happy, cheerful and understanding person. Not only with her family, but also with many friends.

Mom (Virginia) was my loving heavenly wife for 60 years. We were married on June 25, 1942, and our love and respect was forever. Mom was the devoted and supportive mother of our three children, Richard, Carol and Joan, and their

Remembering Virginia

The Frankel family Promise Fund page

Covering All the Bases Campaign Exceeds $50,000 Goal

By Kristi Koon

Each year, The ALS Association participates in the 4-ALS Awareness initiative in cooperation with Major League Baseball. In July, The Association launched its annual Covering All the Bases hitting challenge. This online challenge encouraged the ALS community and baseball fans everywhere to join in the fun and rally support and interest nationwide in the fight against Lou Gehrig's Disease.

Pledge Information

Select a giving level from the options below.

*Choose Your Giving Level:

○ $25.00
○ $50.00
○ $100.00
○ $200.00
○ Donor Designated Amount

Honor/Memory Information (optional)

☐ Yes, this is an honor or memorial gift

Hundreds of generous supporters donated more than $50,000 to advance ALS research, support critical care and services, and continue our public policy efforts on Capitol Hill. The ALS Association is very grateful for all of those who participated in the challenge and brought us one step closer to our vision of creating a world without ALS.

A Company Culture of Support

By Liz Hall

In Lebanon, a suburb of Nashville, Tenn., employees at Permobil's state-of-the-art facility assemble and ship thousands of power wheelchairs every year. Like many manufacturing companies, Permobil pays close attention to safety, quality, production times and customer service; however, something else makes them stand out—they place a priority on serving people with ALS.

A long-time financial supporter of The ALS Association through events such as the Walk to Defeat ALS®, Permobil has provided free wheelchair equipment repair service for people with ALS during the annual National ALS Advocacy Day and Public Policy Conference and donated important equipment to families in need across the country. The company and its employees are committed to the full mission of The Association.

"At Permobil, we understand the urgency of a disease that progresses as quickly as ALS, and it is important to us that people with ALS do not wait any longer than necessary for a piece of equipment that plays such an important role in a person's daily life," said Larry Jackson, Permobil's President of North American operations.

This dedication to people with ALS goes beyond traditional corporate sponsorship and is ingrained in the culture of the people who work at Permobil—from senior leadership to production line workers. What is especially impressive about the Permobil culture is that once an order is received from a person with ALS, it is fast-tracked and out the door to be shipped within 48 hours. To ensure the utmost quality and speed in assembly, ALS orders are flagged with a special red folder.

This philanthropic culture helps build a strong relationship between the work Permobil employees do every day and the impact they make in the lives of the people who are served. This passion is evident on the faces of the dozens of team members who participate in the Nashville Walk to Defeat ALS each fall.

To them it is more than being part of a fun day; it's about a shared vision of a world that is better for people with ALS.

Recording Artist Vince Gill shown with the Permobil golf team at The ALS Association Tennessee Chapter Golf Tournament in April 2013: Larry Jackson, Eva Holmgvist, Darin Lowery, Vince Gill and Barry Steelman

Extension of the IRA

There is now an additional way to make a tax-efficient gift to The ALS Association: an Individual Retirement Account (IRA) Charitable Rollover. Extended as part of the American Taxpayer Relief Act of 2012 (section 208), **the IRA Charitable Rollover allows individuals age 70½ and older to make a gift of up to $100,000 per year to 501(c)(3) charities.**

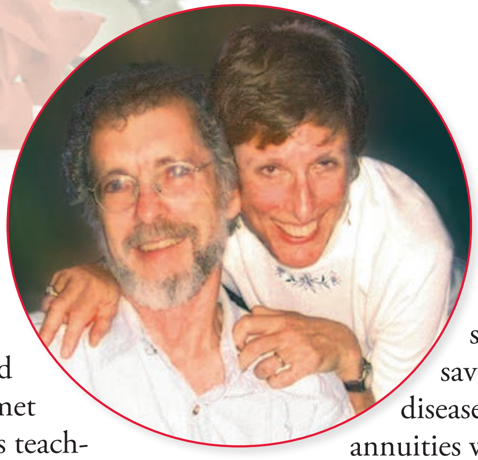
How to make an IRA Rollover Gift to The ALS Association in 2013:

- Contact your IRA custodian to make a gift from your IRA before December 31, 2013
- Distributions must be made from a traditional Individual Retirement Account or Roth IRA
- Distributions must be payable directly from the IRA custodian to The ALS Association
- You are not required to count the distribution as income for federal income tax purposes

Thank you for considering the IRA Charitable Rollover as part of your giving to The ALS Association. For more information, please contact David Moses, Director Gift Planning at (888) 949-2577 or dmoses@alsa-national.org.

A Lasting Legacy of Marital Devotion

By Phyllis Freedman



Bob Smith and Eileen Blau

They say that opposites attract and that was certainly the case with Eileen Blau and Bob Smith. Their long and happy marriage lasted more than thirty years, until Bob's death from ALS. Though the two met in Honduras while Bob was serving in the Peace Corps and Eileen was teaching English at the binational center, that's pretty much where the similarities ended. Bob grew up in a small town, Eileen in New York. Bob was a quiet man, while Eileen, by her own admission, is "not quiet at all!"

But the two did share a love of education and teaching. After obtaining graduate degrees, Bob secured a professorship in the math department at the University of Puerto Rico where Eileen also taught in the English department. He was also very handy. In fact, friends referred to him as "Bob the builder."

The two had wanted a home in the United States, so while living in Puerto Rico, they invested in property "off the grid" in New Mexico. "He fell in love with the land and wanted to retire there," Eileen recalled. Over many summers Bob, with his own hands, built a cabin for the two of them. "Bob was a very special man," explained Eileen. "He was a teacher but he was also extremely handy. That's why it was an especially cruel irony that Bob's first ALS symptom was an inability to lift his arms to write on the blackboard."

Since Bob's death, Eileen has worked to honor Bob's memory. The last summer they were in New Mexico, they contacted the local ALS Association Chapter. Eileen continues to volunteer with the New Mexico Chapter today.

She also honors Bob's memory by maintaining the cabin in New Mexico. "It's Bob's gift to me. It's so tranquil and beautiful, a perfect retreat, and I know Bob's spirit is there. It's the place he wanted to be."

The most important memorial Eileen has created to Bob is her passion for funding ALS research—her top priority. "ALS is an orphan disease. It frustrates me that we still don't know much about the causes or treatments," she said. "I want part of Bob's legacy to be saving others from having to confront this terrible disease." She has established three charitable gift annuities with The ALS Association—one to benefit each of Bob's brothers and one for herself.

"The whole concept of a charitable gift annuity is a wonderful thing. Each of us gets an assured income and a tax break, and the principal will go to something I believe is important—funding ALS research.

For information about charitable gift annuities, contact David Moses at dmoses@alsa-national.org or (888) 949-2577. You must be 60 years of age or older and our minimum donation to establish a gift annuity is $10,000.

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 of $20,000 to The ALS Association 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	70	75	80	85
Your payment will be	5.1%	5.8%	6.8%	7.8%
Your annual payment will be	$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, 2013. Rates subject to change.

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

For more information or a no obligation proposal,
call (888) 949-2577 or email dmoses@alsa-national.org

Community of Hope for Those Who Care

By Kristi Koon

With no known cause or cure, ALS challenges the human spirit and tests the courage of everyone touched by this devastating disease. It affects families, friends, co-workers and communities. The Community of Hope website gives strength and hope to loved ones, neighbors and friends facing the fear and uncertainty of ALS by providing a place to pay tribute to a friend or loved one affected by ALS and raise funds to support the mission of The ALS Association.

Each Community of Hope tribute is a personalized online fund designed to honor or memorialize someone special and features personal stories, photos and videos. The funds raised are critical to ALS research, vital care services and, ultimately, the discovery of a cure. The Association invites everyone to visit the Community of Hope site and to consider establishing a tribute page or contributing to an existing page.

The ALS Association is currently making improvements to the site to provide fund creators with greater capabilities for videos, guest books and fundraising tools. Visit www.community-hope.org today and help us build a stronger Community of Hope.

Online Funds to Honor & Remember

Become a member of the Community of Hope by making a gift or starting your own personal Fund. By honoring those affected by ALS, our community grows stronger everyday and we get closer to a cure.

Did You Know?

The onset of ALS is insidious with muscle weakness or stiffness as early symptoms. Progression of weakness, wasting and paralysis of the muscles of the limbs and trunk as well as those that control vital functions such as speech, swallowing and later breathing generally follows.

Get Involved

- Donate To A Fund
- Create Your Own Fund Page
- Tell Your Friends And Family
- Sign A Guestbook
- About Community of Hope

Share Your Story

We know that Lou Gehrig's Disease has changed your life in a very profound way. This your opportunity to share your ALS experiences with everyone you know so that they too will be inspired to make a significant impact for those affected by this unforgiving disease.

www.community-hope.org

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Dated Material

Walk to Defeat ALS® Growth Continues

By Audri Coffer

In 2000, The Walk to Defeat ALS® began as a small group of committed citizens joining together to walk in honor of their loved ones suffering from this devastating disease. Thirteen years later, that small group has now grown into a nationwide campaign and The ALS Association's largest annual fundraising event. Since its inception, the Walk has raised more than $159 million, and each year approximately 175,000 people participate in 170 Walk events held in 45 states, generating revenue to support care services, research and public policy at the federal, state and local levels.

Every 90 minutes someone is diagnosed with ALS, and every 90 minutes someone loses their battle to the fatal disease. The Walk to Defeat ALS is about much more than simply fundraising. It raises awareness about Lou Gehrig's Disease and brings together those with ALS, their families and others that are in some way touched by the disease, uniting them to realize that they are not alone in their fight against ALS.

Natalie Doering, a high school student and an Omaha Nebraska Walk to Defeat ALS participant, can attest to the event's significance. "The only time that I came close to unmasking my grief and coming to grips with my grandmother's death from ALS was the Walk to Defeat ALS®," said Natalie. "Raising money for The ALS Association not only helps further research, but also helps those who are already dealing with the effects this disease has inflicted. Every dollar raised goes to benefiting the cause."

This year's Walk to Defeat ALS fundraising goal is $23.5 million. Join us in the fight against ALS and participate in the Walk by visiting www.walktodefeatals.org for more information.