

VISION

CREATING A WORLD WITHOUT ALS

VOLUME 4 FALL 2010



alsa.org

Multidisciplinary Care Makes a Difference

By Amber Walters

The ALS Association Certified CentersSM specialize in the management, care and support of people with ALS, providing resources and clinical expertise from a multidisciplinary team of experts, which make it easier for patients to cope effectively with ALS and live the highest quality of daily life.

Studies have shown that the multidisciplinary team approach has a positive impact on a patient's longevity. In October 2009, the American Academy of Neurology released new practice guidelines developed by a team of ALS experts. The guidelines say that ALS multidisciplinary clinics optimize healthcare delivery, prolong survival, and may also enhance people's quality of life. "The Centers are the most comprehensive way for us to manage patients," says Todd Levine, M.D., Medical Director of The ALS Center at Banner Good Samaritan Medical Center Phoenix.

The Centers provide multidisciplinary care at a *single* site, so that patients with ALS and their families can see

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National ALS Registry

By Pat Wildman

What causes ALS?
How can it be treated?
How many Americans
actually have the disease?



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All of us who have been touched by ALS have asked these questions at some point. And we've also heard the answers: that there are no clear answers; that there is no treatment. But that may soon change because the federal government is set to fully implement the National ALS Registry in October!

Beginning this fall, every person with ALS in the U.S. will be able to self-enroll in the registry and provide scientists and doctors with the information they need to answer these and countless other questions that have gone unanswered since ALS was first discovered as a disease more than 130 years ago. Indeed, for the first time, every person with ALS will be counted. And this new data about ALS may help us learn what causes the disease, and how it can be treated or even prevented from occurring in the first place.

But in order for us to realize the promise of the registry, we need your help. Once online enrollment begins, we need every person with ALS to go to the ALS Registry website at www.cdc.gov/als and sign up. And we need everyone in the ALS community to spread the word about the registry to people across the country and encourage them to enroll. The ALS Association will provide tools to help you on our website (www.alsa.org), including instructions on how to enroll, fact sheets and answers to frequently asked questions.

At the same time, we still need your help and active participation in our advocacy programs that have made the registry possible. After all, we need to continue to reach out to Congress and secure the funding that is necessary

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People with ALS Stay in Touch Through Virtual Support Groups

Virtual support group members use an inexpensive web camera connected to a computer to remotely participate in meetings held by some ALS Association chapters. Currently, groups are available for people with ALS, caregivers and family members. Participants log and call into a web conferencing program where they are able to see and talk with other participants. The goal of the virtual support group program is to provide a supportive community for people who are isolated by ALS progression, geography or other circumstances.

"I look forward to the virtual support group each month. There are always new people to meet and new challenges to discuss," said Ken Ludwig, who is the primary caregiver for his wife. "The ALS Association has done a fantastic job of thinking through the real world issue of time availability for caregivers."

Although each support group is unique and reflects individual members' preferences and interaction style, you can generally expect:

- Up to eight web cameras, which allow participants to see one another
- A meeting that typically lasts for one hour, which provides the opportunity to share stories and experiences
- Sharing of valuable information from experts in ALS and other group participants.

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



Jane H. Gilbert

Since our last issue, there have been several exciting advancements in the progress against ALS. This includes a study of the homogeneous population in Finland, where researchers discovered that the origin of a major cause of familial ALS is located on chromosome 9p21. A San Diego, Calif., research team led by Don Cleveland, Ph.D., has gained new insights into the mechanism that causes the SOD1 gene to mutate. And, it has been revealed that a Phase III study of dexamipexole is scheduled to begin in the first half of 2011, which could lead to a new treatment for ALS. Every step forward is good news as we battle this disease.

The ALS Association has used social media, such as Twitter, Facebook and YouTube, for several years. However, at the request of many people in the ALS community, The Association has increased the use of social media as an outlet for information and to dialogue with the community. This is proving to be an effective way to share information and to respond to questions about the disease. It also provides people with a forum to share their experiences and to offer constructive criticism and ideas about how we can improve our organization. We encourage

you to visit our social media sites and join in the conversation.

As many of you know, our headquarters' office is now located in Washington, DC. This allows The ALS Association leadership to more effectively interact with the agencies that are responsible for overseeing the government ALS research and to dialogue with Members of Congress who make decisions about research funding. We also have offices in Chicago, Ill., and Calabasas, Calif., as well as our Chapters and Centers across the United States.

As we continue to commemorate 25 years of dedicated service to the people and families who live with Lou Gehrig's Disease, all of our offices work with great resolve to continue the fight against this dreadful disease with ever-increasing enthusiasm. Our purpose and our vision remains: to create a world without ALS. We appreciate your support and welcome everyone to join us in this quest.

2.

Multidisciplinary Care

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a wide range of clinical experts at each visit.

Every Center is under the direction of a neurologist specializing in ALS, with the support of a professional staff that delivers physical

therapy; occupational therapy; respiratory therapy; nursing; registered dietitian services; speech and language pathology; and social work services. "What I find most helpful from the staff is that after my visit to the clinic I receive a letter with each discipline reminding me of their recommendations," said Celeste Mullenex, who received service from an ALS Association Certified Center. "This is important because I always see something I'd already forgotten! It is so great to see so many specialists in ALS in just one trip."

People with ALS visit a Center's multidisciplinary team for a full morning or afternoon about every three months and are motivated by their desire to do all they can to deal effectively with ALS. "Patients who come to the Centers want to be proactive, addressing questions and problems before they arise and working with leading experts in ALS," says Eric Sorenson, M.D., Director of The ALS Center at Mayo Clinic Rochester. "Having a team that works together—rather than seeing patients through separate visits in different locations and organizations—helps to ensure that specialists are addressing the big picture."

In addition, there is an ALS Association Chapter liaison that attends clinic days and provides information about support groups and other services they offer to help people with ALS and their families deal with any challenges they may face. Kim Hughes, Arizona Chapter Director of Patient Services, says, "We work hard to help people use their financial resources where they need it most, and we provide help on the details of insurance, Medicare and Medicaid."

Even though the Certified Centers across the United States use a variety of approaches to organize and run their clinics, they all share these same essential features:

- A **collaborative multidisciplinary team** works together to provide answers and solutions to patients and their families during and in between visits.
- The **patient's treatment decisions are shared** by the team, and patients are encouraged to be active participants, ask questions and express their thoughts and opinions. "I believe in being proactive in dealing with problems. Being involved in the clinic helps you be in control of the situation and prepare for changes before they occur," says Dennis Hoyniak, a person with ALS from Vermont.
- Centers focus on maintaining function and treating symptoms to **help patients achieve the best possible quality of life**.
- The medical director is **involved in ALS**

research, meaning the Centers are at the forefront of best practices in ALS treatment and drug therapy. Research information is shared directly with patients to help them gain greater insight into the nature of ALS and to learn about new clinical trials, therapies and approaches to the disease.

- **Each Center is regularly evaluated** by an ALS Association committee, whose members are all from Certified Centers and are familiar with the national standards of care.

E. Peter Bosch, M.D., Medical Director of The ALS Center at Mayo Clinic Scottsdale, notes that patients who come to the clinics have already been diagnosed with ALS, so the Centers are dedicated to maintaining the patients' level of functioning and assisting them with their everyday activities. "And we offer people hope," he says. "That's very important."

For a full listing of The ALS Association Certified Centers, please visit our website at www.alsa.org.

Ohio Family Charters Buses for ALS Awareness Day

By Amber Walters

On June 13, 2010, the Cincinnati Reds stadium was full of cheering fans. As far as the eye could see were red T-shirts emblazoned with the trademark Cincinnati Reds logo. However, on closer observation, more than 200 shirts displayed the words: "HOPE LOVE CURE." The red color was not only for the team, but also for the Major League Baseball/ALS Association ALS Awareness Day, the "Team O" Walk to Defeat ALS® team, and the person with ALS who they were all there to support, Dan Mangas.

It started with some friends and family and one chartered bus. By the day of the event, Linda, Dan's wife, had arranged for two additional charter buses to take the 251 friends and family from Liepsic, Ohio, to Cincinnati to go to the Reds game, an approximately 300-mile round trip.

"We have never held an ALS Awareness Day with the Cincinnati Reds where a family brought so many people to the event," said ALS Association Central and Southern Ohio Chapter Executive Director Marlin K. Seymour.

Each year during the annual event, the chapter chooses someone to go onto the field and throw out the first pitch, and this year Dan's family was selected. When Dan, Linda, and their two children, Nate (16) and Nicole (12), went onto the field, they were met by Reds outfielder Chris Heisey, who was there to catch Nate's pitch. This was especially meaningful as Heisey's father died from ALS in 2007.

Nate, a baseball player and avid Reds fan, said, "It was cool to be down on the field

and throw out the first pitch in honor of my dad." After the pitch, Heisey signed and presented the baseball to Nate. Post game, Heisey surprised Nate with another gift, an autographed bat with the words: "Keep the faith" and gave Nicole an autographed batting helmet with: "God Bless" printed on it.

Linda recalled, "It was a great day, everybody had fun," and Dan added, "I had a wonderful time that day."

In addition to raising awareness about ALS at the Reds game, Dan and Linda attended the National ALS Advocacy Day and Public Policy Conference this past May in Washington, DC, and last year, organized "Team O" for the Walk to Defeat ALS. This year, the whole family is gearing up again for the Walk to Defeat ALS in a variety of ways. Nate's girlfriend, a cheerleader, organized a car wash fundraiser. Linda is holding raffles at her office and planning a taco dinner before one of Nate's upcoming football games. Nicole organized what is called a "stall day," where students bring in coin donations and school doesn't start until the teachers have counted all the change.

Of all these events, Linda likes to say, "It helps to keep the fun in 'fundraising!'" Last year their hard work and efforts raised an inspiring \$13,000. This was more than expected, as was the attendance and support from so many of their friends and family at the Reds game. It is, however, a testament to the Mangas family and their commitment to bring their community together to raise awareness about ALS, even if means chartering extra buses.



Nate and Heisey

Program Helps Families with ALS Coordinate Care

You don't have to be alone on this journey.

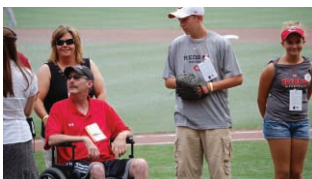
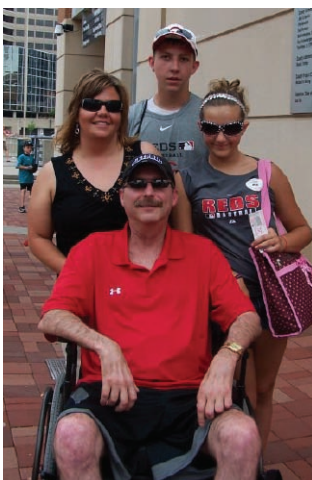
It's easy for people with ALS and their families to become overwhelmed by the wide range of needs they have, from running everyday errands, making meals, and maintaining their home, to getting children to and from school, and so much more. It's hard to know when and how to ask friends and neighbors for help, and how to organize their availability.

The Care Connection program is simple: it's a network of volunteers from the community—friends, neighbors, members of community organizations such as a church, or other service groups—that provides help for people with ALS and their family, and even gives the caregiver a break from their day-to-day responsibilities. 3. To learn about personal experiences with the Care Connection, view the video at <http://www.alsa.org/patient/caregivers/careconnection.cfm#video>.

The program provides a plan for organizing help, training and information about what approaches tend to be most effective.

The Care Connection uses a website—lotsahelpinghands.com—that allows volunteers to sign in and see the community calendar where tasks have been posted by a volunteer coordinator.

Call your local ALS Association chapter to see if it is featuring the Care Connection program, or call the national office of The ALS Association for more information. The office is open every business day from 7:30 a.m. to 4 p.m., Pacific Time at (800) 782-4747 or alsinfo@alsa-national.org.



Top: "Team O" Walk to Defeat ALS team arrives at Reds game.

Middle: Dan Mangas and family.

Bottom: Mangas family on the field with the Reds.

Only God Has Heard Him Cry

By Kelly Calvanico

In May 2010, during ALS Awareness Month, ABC's *Extreme Makeover: Home Edition* brought ALS awareness to more than 10 million television viewers. The show featured Jeremy Williams, a high school football coach with ALS, and highlighted the impact that this devastating disease can have on a family's emotional and financial resources.

In 2005, Jeremy sought medical care after a hand injury. After three years of doctor visits and medical tests, he was diagnosed with ALS. The Williams' youngest child, Jacob, was born with Spina Bifida and is paralyzed from the waist down. As of the taping of the show, Jeremy was having trouble walking and would soon require the use of a wheelchair. The Williams' home was too small to accommodate two disabled people. Already, Jennifer had to carry six-year-old son Jacob throughout the house, a feat that would become impossible as Jacob continued to grow. With a cracked foundation, leaking retention wall and mold in the walls, the house was literally crumbling around them. The Williams were facing medical and home repair bills that seemed insurmountable.

Even as Jeremy and Jennifer were struggling to hold their family together in the face of adversity, Jeremy was bringing hope and inspiration to the small town of Greenville, Ga. Jeremy has been the head football coach for the Greenville High School football team for the past eight seasons. Following his diagnosis with ALS, he continued to coach his team, leading them to an 11-0 season and into the playoffs last fall. His inspirational leadership earned him the High School Coach of the Year Award.

Thanks to *Extreme Makeover: Home Edition* team, Nationwide Homes and hundreds of local volunteers, the Williams received a new

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The Laureate Society Races to Treat and Cure ALS

By Dan Gordon

At first glance, Larry Barnett and Cynthia Denton Douthat appear to have little in common. But Barnett, a Los Angeles attorney whose family has been one of The ALS Association's longest and most ardent supporters, and Douthat, an Atlanta resident who has worked tirelessly for more than 25 years at the local and national levels on behalf of people with ALS—and who lost both her father and husband to the disease—now share something more than their interest in supporting The ALS Association. They are the first two members of the newly established ALS Association Laureate Society—Barnett representing his family, and Douthat representing her family and the Keith Worthington Chapter.

The Laureate Society provides entrepreneurial supporters of The Association with a “place at the table” in guiding the organization's direction and establishing strategic priorities. Membership—which is open to individuals, families, foundations and corporations—requires a gift or pledge of \$1 million or more over a maximum five-year period. Members will work collaboratively with The ALS Association board and staff and its scientific advisory boards in support of the full mission of the organization.

Meeting twice a year, Laureate Society members will review and recommend projects for funding as well as provide counsel. Among other things, they will help to influence the formation of public policy and public funding for ALS; promote the scientific work of leading researchers, with whom they will have a personal connection; and support the work of ALS Association chapters, centers and clinics throughout the United States.

“These two gifts provide great momentum and incentive to do exactly what the Barnett family has envisioned—to find more forward-thinking donors to come to our table and commit their time, money and wisdom to help us achieve our goal,” says ALS Association President and CEO Jane H. Gilbert. “These inspiring families—and the networks that are supporting them—are the first of many Laureate Society members who will help us guide and pave new pathways that will lead to the elimination of ALS.”

As one of the first two Laureate Society members and the inaugural chairman, Barnett has taken a major leadership role in the new society—not only contributing the \$1 million donation to join, but also making a leverage grant—the promise of an additional \$1 million when the Laureate Society gains at least three new members. The gift continues a long history of unwavering support for The Association by the Barnett family.



Lawrence and Isabel Barnett

Lawrence R. Barnett, the former president of Music Corporation of America (MCA) and Larry Barnett's father, realized early in his life that helping the less fortunate was a calling far more important to him than achieving fame and fortune. In 1978, when the wife of a close friend developed ALS, Barnett turned his philanthropic attention to the disease and became a guiding force behind the founding of The ALS Association, serving as its first chairman in 1985. He has continued to play an active role in the organization's funding and development and today, at 97, serves as Chairman Emeritus. His wife, Isabel, was an equally ardent supporter and their children are intent on carrying through the couple's vision.

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The Laureate Society

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"I am proud to continue my family's legacy of support," says the younger Barnett, who followed in his father's footsteps by joining The Association's Board of Trustees last January. "For more than 30 years, my father has been dedicated to helping people who suffer from this terrible disease and to finding a cure. It's a cause that continues to be very dear to his heart, and we are excited to see The Association expand its fundraising efforts in this way."

Cynthia Denton Douthat, the second Laureate Society member, also has a long history of support for The ALS Association, although her involvement began at the local level and was sparked not by the diagnosis of a friend, but of her father and, two decades later, her husband.

In 1984, Douthat's father Jack Denton was diagnosed with ALS. Douthat, a newly divorced mother of three, moved from Texas to her hometown of Kansas City to help with his care, and realized how important a supportive network could be. She looked ALS up in the phone book, found the number for her local ALS Association chapter, and ended up speaking with Sue Worthington, wife of Keith Worthington, after whom the chapter is now named. As her father's disease progressed and following his death in 1987, Douthat immersed herself in volunteer work. She joined the chapter's Board of Directors and started its first walk fundraising event, which included the "Jack Denton Mile."

A few years later after her father's death, Douthat lost her youngest son, Jeff, as a result of an automobile accident. Devastated, she leaned on her friends at the Keith Worthington Chapter for

support. By now, Douthat's commitment to the ALS cause was such that she requested that gifts in her son's memory be made to The ALS Association.

One positive resulted from the tragedy: It reunited Douthat with her high school sweetheart and best childhood friend Marsh. When he came to pay his respects, their relationship was rekindled. In 1993 they were married. Now living in Atlanta, Douthat became an active volunteer with the

Georgia Chapter, participating in both fundraising and patient services-related activities and eventually joining that chapter's Board of Directors. "I brought Marsh into the world of ALS," she recalls, "and if it was important to me, it was important to him."

When her husband began to experience the muscle twitching that Douthat knew to be characteristic of ALS, it seemed impossible, but in 2005, Marsh and Cynthia received the unthinkable news.

Two years later—20 years to the month after Cynthia's father had died—Marsh succumbed to the disease.

Cynthia and Marsh Douthat

The loss only strengthened Douthat's resolve to devote herself to fighting the disease and helping those who are affected. In 2009 she became a member of The ALS Association's Board of Trustees. In conjunction with the Keith Worthington Chapter, the Douthat family established the EMD ALS Biomarker Research Fund and committed to raising \$1 million over five years from private individuals in memory of Douthat's late husband (whose initials are in the fund's title). Already, they are halfway there.

"This is my passion," Douthat says of her ALS activism. "It's what I'm supposed to do."

For information about The Laureate Society, contact Gordon Lavigne at (202) 407-8584 or glavigne@alsa-national.org



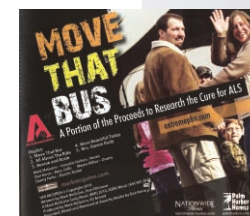
God Heard Him Cry

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home equipped for their current and future needs. The show featured a Nationwide Homes modular home, the first to be featured on the show, and challenged the *Extreme Makeover* team to build the home in just seven days. The new home included an accessible kitchen and bathrooms, hallways wide enough to accommodate two wheelchairs, remote controlled doors, a therapy room and a ceiling mounted track system which would allow Jeremy to move independently as his mobility continues to decline. The *Extreme Makeover* team also tackled the Greenville High School Field House, making the facility accessible for Jeremy and naming it in his honor.

The family received additional good news on the show, learning that CVS Pharmacy would pay off their medical debts. Nationwide Homes hosted a series of fundraisers, raising enough money to pay off the Williams' mortgage and spreading ALS awareness by distributing informational materials about the disease.

Inspired by Jeremy Williams' story, Nashville recording artist Mark McGuinn wrote and recorded a song entitled *Move That Bus*.



The song pays tribute to Jeremy's strength in the face of adversity with the lyrics, "Only God Has Heard Him Cry." McGuinn has committed to donating a portion of all earnings from the song to The ALS Association. To purchase the song online, go to www.extremephpn.com. A portion of the proceeds will be donated to research to find a cure for ALS.

The ALS Association would like to thank ABC's *Extreme Makeover: Home Edition*, Nationwide Homes and Mark McGuinn for their support of the Williams family and for raising awareness about ALS.

State-of-the-art Facility for People with ALS

Recently, the Leonard Florence Center for Living held the grand opening of the Steve Saling ALS Residence, said to be the nation's first and only, fully automated, skilled service residence for people living with Lou Gehrig's Disease. Saling is a landscape architect, who specialized in designing ball fields, plazas and streetscapes for 13 years until he was diagnosed with ALS in 2006.

Located on Admiral Hill in Chelsea, Mass., the groundbreaking for the facility was in August 2008. The ALS residence bedrooms include a fully accessible bathroom and cutting-edge assistive technology, such as Proximis Enterprise Automation Controller (PEAC), which is an automation solution for palliative care. The technology allows residents to access a command center, composed of

6. computerized sensors to open and close doors, turn lights on or off, and surf the web. As a result, residents with ALS are able to take the elevator to the lobby café, venture outdoors to the veranda, and order a cold drink from the lobby café via email.

The Leonard Florence Center for Living is a unique concept intended to deinstitutionalize long-term care with its own dedicated staff of nursing assistants and certified caregivers who are trained in CPR, first aid, culinary arts, and communications. A physician and clinical support regularly visit the residence. The concept was integrated by Barry Berman, CEO of the Chelsea Jewish Foundation, and Steve Saling, who assisted with the plans for the facility, including the promotion of ventilator support for each room.

"I was so pleased to be included and represent The ALS Association as they celebrated the opening of the beautiful Steve Saling ALS Residence," said Jane Gilbert, president and CEO of The Association. "It is truly a

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Quilters Give Warmth and Cheer to People with Lou Gehrig's Disease

By
Stephanie
Dufner

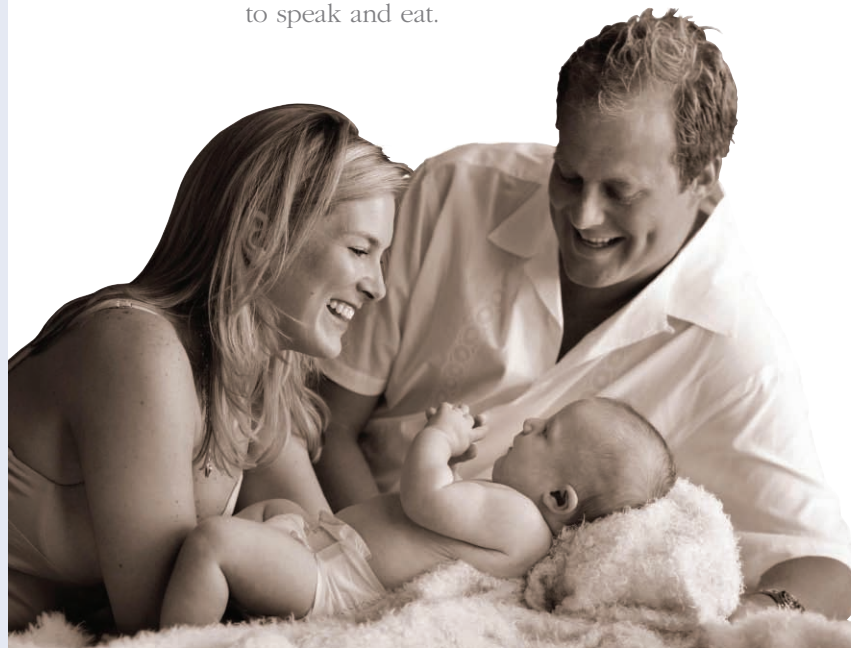
*"A quilt
will warm
your body
and comfort
your soul."
—Anonymous*

This adage holds special meaning for the artists who participated in The ALS Association's Hopes & Dreams™ Quilt Challenge for ALS, a contest launched in October 2009. The challenge had multiple purposes: providing warm hand-made quilts, offering hope and recognition to individuals battling Lou Gehrig's Disease, increasing awareness of ALS, and raising funds for treatments and a cure.

Originally expecting about 200 entries, more than 1,200-plus quilts have been gathered from this event, most of which will go to ALS patients across the country.

"The response to the challenge has been truly wonderful and heartwarming," says Kathy Thompson, founder of the Hopes & Dreams contest and co-owner of Quilters Dream Batting in Virginia Beach. "I am delighted, amazed and very touched by the reaction that we have received."

Thompson presented the idea for the quilt challenge to The ALS Association's DC/MD/VA Chapter to honor her son Josh Thompson and others coping with ALS. Josh, 36, has lived with ALS since 2007; this once energetic husband and father of two young children is now completely paralyzed and has lost the ability to speak and eat.



"Kathy's quilt project has resulted in an incredible outpouring of warmth and support for her and her family, and it will benefit all of our PALS," states Ronnie Gunnerson, executive director of the DC/MD/VA Chapter.



Josh Thompson

Contestants were to submit quilts measuring 35" x 44" or larger by July 31, 2010, and include a message. Most quilters designed pieces in memory or in honor of a loved one with ALS. "Many quilts were accompanied by beautiful, touching stories, notes and well wishes," adds Thompson.

Contest winners will receive cash and/or quilting materials such as fabric or patterns. Categories include "Sew Creative," for the quilt that best reflects the "Hopes & Dreams" theme and "Sew Prompt" for the first six individuals who donated quilts.

The ALS Association will distribute the quilts to its chapters nationwide. Cathy Easter, regional director at the DC/MD/VA Chapter, says chapters can distribute the quilts "as they wish—at support group meetings, chapter events, or during patient home visits."

In September, recording artist Bruce Hornsby performed at a benefit concert in Virginia Beach, and some of these quilts were on display. Attendees had the opportunity to bid on the quilts in a silent auction. In addition, some of the quilts will be sold in an online auction that will take place in October 2010. For more information, visit <http://www.quiltersdreambatting.com/HD/ALS.htm>.

Thompson plans to repeat this contest in 2011, proudly saying, "We are already starting to receive quilts for our 'second annual' Hopes & Dreams Quilt Challenge for ALS."

To read more about the Hopes & Dreams Quilt Challenge for ALS, visit the following website: <http://www.facebook.com/pages/Quilters-Dream-Batting-sponsoring-Hopes-and-Dreams-Quilt-Challenge-for-ALS/150913912237?v=wall>.

Joy and Josh Thompson with their baby, Wyatt.

Remembering E.G. with a Legacy of Hope

By Katie Sweeney

Even at age 79, E.G. Booth was a fountain of energy. Many days, he swam a half-mile in the pool at a local Iowa college. He played trombone in three bands, volunteered for several charities and mowed lawns at his family's farm.

But in April 2003, E.G.'s energy was waning. His back and hip hurt, and his trombone case suddenly seemed too heavy. As the summer progressed, he was getting stiffer and weaker.

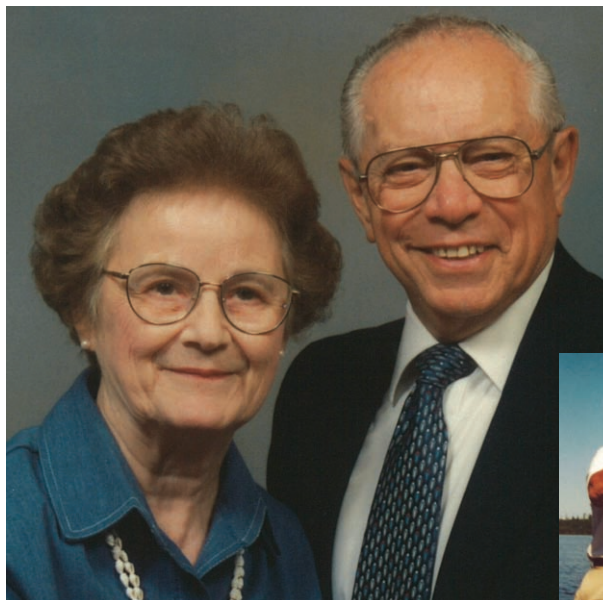
In November, after 25 doctor visits, a neurologist in Iowa City finally gave E.G. and his wife, Carol, a definitive diagnosis: ALS. Although his breathing was declining, E.G. still kept up many of his activities.

"He never complained," says Carol, who recalls that E.G. received very helpful information from the medical staff at The University of Iowa Hospitals and Clinics about what to expect as the disease progressed. On Jan. 21, 2004—just two months after his diagnosis—he died suddenly while watching TV at home with Carol.

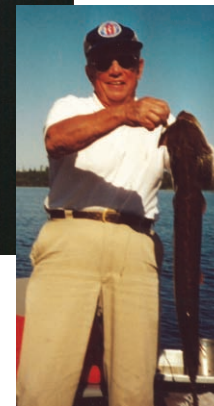
"There was no warning whatsoever," Carol recalls. "It was startling to have it be over so fast."

Shortly after his death, Carol received a letter from Jason Lee, the executive director of The ALS Association's Iowa Chapter. Impressed with The Association's work to find a cure for ALS and support patients and families, she began making donations to the chapter. Recently, with the full support of her children, she decided to make an even bigger difference by naming The ALS Association as a beneficiary in her will.

"In addition to working on the science of ALS, The ALS Association genuinely cares about the people and



Carol and E.G. Booth



families affected by this disease," she explains. "That means a great deal to me." Originally from Philadelphia, Carol met E.G. while working as a horseback riding instructor at a summer camp in Connecticut, where E.G. was the athletic director. By the end of the summer, they were engaged. The couple settled in Grinnell, Iowa, where E.G. worked as a professor and track coach at Grinnell College. They later moved to Indianola, Iowa, where he headed the education department at Simpson College for 30 years.

The Booths were married for 54 years. In addition to their four children, Carol has four grandchildren and four step-great grandchildren adopted from Russia. She still lives in Indianola, where she volunteers for community and charitable causes, plays hand bells in her church choir and directs a chimes choir.

She hopes that more people will join in supporting The ALS Association's mission.

"There are so many people who have never even heard of ALS," she notes. "We need to spread the word and help fight this disease."

State-of-the-art Facility

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remarkable space where people living with ALS can enjoy the independence and dignity they deserve."

In addition to speaking at the grand opening ceremony, Gilbert presented the ALS residents with handmade quilts from The Hopes and Dreams Quilt Challenge for ALS, a project launched by Kathy Thompson of Virginia Beach, Va. in conjunction with The ALS Association DC/MD/VA Chapter. See the article on page 6 in this issue of *Vision*.

"It was an honor to deliver the quilts," added Gilbert. "And, The ALS Association applauds Steve and the foundation for their vision and will to complete this wonderful facility."

7.

Virtual Support Groups

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Barbara Hopcroft, patient services manager for The Association's Massachusetts Chapter shared this, "I think that the virtual support group is the future—a support group without wheels. Connecting with people electronically, hearing and seeing them, and having helpful conversations without leaving home is a great service to offer PALS and CALS."

Contact your local ALS Association chapter to find out if they host virtual support group meetings. For additional information about virtual support groups, contact the national office at (800) 782-4747 or alsinfo@alsa-national.org.

ALS Registry

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to move this vital project forward. So please make sure you are signed up as an ALS Advocate via our website at www.alsa.org/policy/involved.cfm.

The ALS Association and advocates like you led the fight to enact the ALS Registry Act and secure congressional funding to build the registry. And together, we can continue to create the roadmap that will lead to a treatment and cure for Lou Gehrig's Disease.

The National ALS Registry is Coming! **by the Agency for Toxic Substances and Disease Registry**

Defeating amyotrophic lateral sclerosis (ALS) will take teamwork—physicians, scientists, researchers and patients working together. Indeed, progress in recognizing and treating the disease has come about because of a team effort. And because of the teamwork of ALS patients and their advocates, the National ALS Registry will soon be a reality.

In 2008, Congress charged the federal Agency for Toxic Substances and Disease Registry (ATSDR) with developing a registry to gather and organize information about people living with ALS. The National ALS Registry represents a ground-breaking step in the fight against ALS. This registry will give researchers data about who has the disease and where it occurs. They can use registry data to detect disease pattern changes over time and to investigate possible common risk factors among ALS patients.

This information can help researchers

- estimate the number of new cases of ALS identified each year;
- estimate the number of people who have ALS at a specific point in time;
- understand who gets ALS and what factors affect the disease;
- examine the connection between ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS; and
- improve care for people with this disease.

To ensure privacy, only certain researchers from ATSDR have access to the database. Individual patient data will not be distributed, but researchers outside ATSDR can request compiled data.

Currently, there is no accurate picture of who has ALS. But the more people living with ALS who participate in this registry, the more accurate the picture will become. Beginning in fall 2010, people living with ALS will be able to add their information to the registry. To learn more about the National ALS Registry, visit www.cdc.gov/als.

The ATSDR, which is implementing the National ALS Registry, is a federal agency of the U.S. Department of Health and Human Services and sister agency to the Centers for Disease Control and Prevention (CDC).

The ALS Association

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The ALS Association to Host the Annual International ALS/MND Research Meetings

On our 25th Anniversary, The ALS Association was chosen by the MND Association to host the 21st International ALS/MND Symposium in temperate Orlando, Florida. Numerous research meetings are scheduled to take place and include:

- Ask the Experts Forum on December 9, which is geared specifically for people with ALS and their families (no registration is required).
- Allied Professionals Forum on December 10, which is focused on practice and experience for health professionals in the care and support of people living with ALS/MND and is a collaboration between the International Alliance and the Motor Neurone Disease Association.
- International Symposium, from December 11-13, which is geared towards researchers, clinicians and allied professionals. It is planned as two parallel meetings, one on biomedical research and the other on advances in the care and clinical management of people affected by MND. Joint opening sessions consider issues of mutual concern, challenging current views and practice.

**To help The ALS Association “create a world without ALS,”
call (888) 949-2577 or visit www.alsa.org/donate.**