

VISION

CREATING A WORLD WITHOUT ALS



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New Discoveries New Enthusiasm and New Commitments to Finding ALS Treatments

By Richard Robinson



New discoveries in amyotrophic lateral sclerosis (ALS) have energized researchers like never before to pursue the causes of ALS and develop new treatments to slow or halt the disease. Those same discoveries have given ALS research a very high profile in the wider scientific community and have brought many new researchers into the field.

The discovery in 2011 of the C9orf72 gene ranks among the most important breakthroughs in ALS research in the past two decades. The heightened interest in the new gene, and in the field of ALS research, was on display in October 2012, at the Annual Meeting of the Society for Neuroscience, the world's largest assembly of neuroscientists. More than 170 researchers gathered at a symposium on the gene co-sponsored by The ALS Association and The Association for Frontotemporal Dementia. Many scientists from other research fields attended, bringing their expertise and insights to share with long-time ALS researchers.

The gene is now the single most common cause of familial ALS and is also responsible for a proportion of sporadic

(non-familial) disease. That makes the gene a prime target for understanding the disease process and developing new therapies, as such treatments are likely to be useful in the widest group of people with ALS.

The field of ALS has also seen other exciting developments recently, including developments in the use of patient-derived stem cells to study the course of the disease. Scientists believe this may offer a uniquely valuable platform for understanding both differences and commonalities in the disease processes in different people. Progress has also been made in development of experimental therapies that target misfolded proteins in ALS. Researchers think that accumulation of misfolded protein may be an early step in the development of the disease. Interrupting that process may hold promise as a therapy.

Inevitably there have been disappointments, too. Like patients and families, ALS doctors and scientists were hoping for a home run from the dexamipexole trial, but in the end, it did not prove effective. Such disappointments, however, only strengthen the resolve of researchers to work harder to truly

Please turn to page 4

RECENT AWARDS

SHEILA ESSEY AWARD FOR ALS RESEARCH

Rosa Rademakers, Ph.D.
Associate Professor of Neuroscience
College of Medicine
Mayo Clinic
Jacksonville, FL



SHEILA ESSEY AWARD FOR ALS RESEARCH

Bryan Traynor, M.D., Ph.D.
Investigator and Chief of the
Neuromuscular Disease Research Unit
Laboratory of Neurogenetics
National Institute on Aging
National Institutes of Health
Bethesda, MD



THE RICHARD OLNEY AANALS ASSOCIATION CLINICIAN SCIENTIST DEVELOPMENT AWARD

James Berry, M.D., M.P.H.
Department of Neurology
Massachusetts General Hospital
Boston, MA



For details, visit www.alsa.org/news/media/press-releases/2013-sheila-essey-award.html

For details, visit www.alsa.org/news/media/press-releases/2013-olney-award.html

Many Spoke to the FDA with One Voice

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



President and CEO
Jane H. Gilbert

In late February, leaders from The ALS Association, along with people with ALS, caregivers, physicians, scientists and other concerned individuals in the ALS community had the opportunity to address a panel of representatives from the U.S. Food and Drug Administration (FDA) during its first-ever public hearing to discuss ALS. The primary message was to urge the FDA to partner with the ALS community to help expedite the drug development and approval process and bring new treatments as quickly as possible to those living with Lou Gehrig's Disease.

Our Chief Scientist, Lucie Bruijn, Ph.D., and I were proud to be among the first to speak of the nearly 60 people representing every segment of the ALS community and almost every major ALS organization in the country. The fact that so many people and organizations gathered in one place at one time speaks volumes about our collective desire to partner with the FDA to speed the development of and access to treatments for ALS.

Dr. Bruijn explained to the panel that we are in one of the most exciting times in the history of ALS drug development. A number of promising treatments are currently in clinical trials, and the pharmaceutical and biotech industries are joining the search for ALS treatments at a greater pace than ever before. Ken McGunagle, the newly elected Chair of our Board of Representatives also spoke during the hearing. "Many people with other serious and life-threatening diseases, like ovarian cancer, have options and hope," said McGunagle, whose wife is an ovarian cancer survivor, and whose father died of ALS six months after being diagnosed. Regarding treatments for ovarian cancer, he continued, "Yes, the treatments are risky and have serious side effects. Yes, they are not always effective. But they provide hope and a chance to be called a survivor. The only survivors with ALS are the loved ones left behind."

As Robert Anderson, a gentleman with ALS who works closely with our Jim "Calfish" Hunter Chapter, so eloquently stated using his computer-generated voice, "ALS is fast. We need the FDA to be faster."

That's the bottom line. People with ALS need a treatment for this horrific disease. They need it now, and we will continue to work with the FDA and all of our partners to find one as soon as possible. After all, people with ALS do not have time to wait.

Continued from page 1

Finding ALS Treatments

understand the disease process, and knowing that is the surest route to finding the most effective treatments.

In order to speed progress and bring the best minds to bear on the problem of therapy development, The ALS Association has formed extensive partnerships with pharmaceutical companies, biotech firms, academic researchers and other non-profit groups. These collaborations have been instrumental in the rapid development of research tools. These include:

- databases of genetic and other disease-related information from which any researcher may access

- cell repositories for patient tissue, open to those engaged in appropriate projects
- development of new mouse and other lab models using the newest genes
- co-sponsorship of meetings and events, such as the Neuroscience symposium, to bring together the widest possible groups of experts.

Hundreds of scientists are committed to meeting the challenge of finding a cure for ALS. The ALS Association is committed to providing them with the resources, the tools and the partnerships they need to do so. With those twin commitments, the field is poised to make rapid progress in the near future.

ALS Athlete Qualifies for U.S. Paralympic Team

By Kelly Anne Keeler

Diagnosed with ALS in 2005, former U.S. judo team member, Dr. Cathy Cummins, is now engaged in the fight of her life.

Cummins, a Portland-based chiropractor, began studying martial arts at the age of five and holds five black belts in various disciplines. She paid her way through college by competing in full-contact prize fighting. Before her diagnosis, she was a cyclist, a swimmer, a runner and a competitive bodybuilder. Now, she struggles to get through the day without losing the energy to complete the most basic tasks.

"ALS is a disease of loss. You have to get really good at losing things," Cummins said. "You are forced to give up 90 percent of the things you love—and must focus on the things

that are important. I have about three good hours a day when I can be active, so I have to make tough choices."

In 2009, just four years after her diagnosis with ALS, Cummins discovered wheelchair curling. Curling is a sport where two teams take turns pushing a 40-pound stone down a sheet of ice toward a series of concentric rings. The object of the sport is to get the

Please turn to page 8

VISION

FEATURES	PAGE
Finding ALS Treatments	1, 2
Recent Awards	1
Message from Jane H. Gilbert	2
ALS Athlete	2, 8
Coach Ernie	3
ALS/MND Symposium	4
ALS Philanthropists	4
Making a Promise	5
ALS Research	6
Empowering People with ALS	6
Legacy of Hope	7
Walk to Defeat ALS	8



HOOPS AND HOPE:

The Enduring Legacy of 'Coach Ernie'

By Katie Sweeney

Every year on a Saturday in May, more than 400 people pack the Calabasas High School gym for the E.F. Wallengren Hoopfest. They come to play basketball, of course. But that's just the beginning.

The event, now celebrating its 10th year, was created in honor of E.F. "Ernie" Wallengren, a Calabasas High basketball coach who died in 2003 after battling ALS for two years. Hoopfest is not only a celebration of Ernie's life, but also a continuation of his final dream: to find a cure for ALS.

All proceeds go to the E.F. Wallengren Fund for ALS Research at The ALS Association. The fund supports stem cell research and was established by Ernie and his family while he was still alive.

"Hoopfest has been a wonderful way of honoring Ernie and the commitment he had to the community, while also raising funds for ALS research," said his mother, Claire Whitaker, who helps organize the event with other family

members. "It's meant a lot to me. I tell people, 'I'm 85 years old, and I'm not going to die until there's a cure for this disease.'"

A television writer and producer of such shows as "Falcon Crest," "Touched by an Angel" and "Baywatch," Ernie also loved basketball. He and his wife, Cheryl, raised five children, and he often volunteered to coach his kids' teams.

Eventually, he became the junior varsity basketball coach at Calabasas High School and started a club team, too—reaching out to include underprivileged and troubled youth he saw hanging out at the gym.

When kids couldn't afford uniforms or trips, he provided them. If they needed a place to stay, they stayed at his house. There were almost always extra plates at the table, and many of those kids went on to play college basketball. Even after Ernie was diagnosed with ALS in 2001, he continued to coach from his wheelchair. When that became impossible, he still attended games and traveled with the team.



Ernie Wallengren

At his funeral, entire church rows were filled with boys in basketball jerseys, saying goodbye to "Coach Ernie." After Ernie's death, two fellow coaches suggested creating a basketball-themed fundraiser—and Hoopfest was born. Initially a low-key affair, the event now features all-day basketball, a three-point shootout, a silent auction, food, T-shirts and even music from local radio station KOST-FM, where Ernie's brother, Mark Wallengren, works as a morning show host. In addition to Hoopfest, family members conduct a twice-yearly fundraising appeal, and they established an ALS Promise Fund tribute in 2011 (www.alsa.org/ErnieWallengren). In all, their efforts have raised nearly \$500,000 over the past decade.

It's a lot of work, but it also brings the family together—and keeps Ernie's memory alive.

"We get back what we put in 100-fold," Cheryl said. "What warms my heart is that so many of the kids he coached still come to Hoopfest, even though they're grown up. They've never forgotten him."



The extended Wallengren family



This year's Hoopfest is May 18, 2013, in Calabasas, Calif. For more information, go to www.dreamscotland.org.

2012 International ALS/MND Symposium and Allied Professionals' Forum

By Cynthia Knoche

In early December 2012, The Motor Neuron Disease (MND) Association in cooperation with the International Alliance of ALS/MND presented the 23rd International Symposium on ALS/MND in Chicago. Supported by The ALS Association, the dual-track biomedical research and evidence-based clinical sessions brought together nearly 1,000 leading international researchers and clinicians.

Breaking laboratory research related to the pathogenesis of this complex disease was presented over the course of three days. Information related to the C9orf72 gene and frontotemporal dementia (FTD), supported by The ALS Association's Research Program, was a highlight of the biomedical research track. Clinical Management studies conducted by staff of The ALS Association Multidisciplinary Certified Centers and Chapters related to cognitive changes, decision making, clinical trial design, multidisciplinary management and potential biomarkers were shared with the international audience.

Poster sessions provided attendees with the opportunity to view hundreds of completed projects or "work-in-progress" studies. Topics funded by The ALS Association included a timely "Emergency Preparedness Guide," as well as projects relating to the cost of care delivered by a multidisciplinary clinic and the cost assumed by those diagnosed with ALS and their families.

With the support of Sanofi U.S. for continuing professional education, more than 150 ALS Association Chapter, Certified Center and Clinic staff traveled to Chicago from across the country to attend the Allied Professionals' Forum. This forum, held in conjunction with the International Symposium, focused on the practical care and support of those living with ALS. Privileged to hear about best practice activities from international experts, clinicians affiliated with ALS Association Multidisciplinary Certified Centers and Clinics presented their expertise related to the impact of caregiving, especially for those diagnosed with ALS and FTD, and family education.

Thanks to the support of Permobil, The ALS Association hosted an Educational Networking Dinner at the Ann Center. Chapter, Center and Clinical-affiliated staff enjoyed the valuable opportunity to network with professional peers from across the country. A special feature of the evening was an intimate "fireside chat" hosted by ALS Association President and CEO Jane Gilbert and Chief Care Services Officer Kim Maginnis. Maginnis shared information related to The Association's Care Services Programs, including a review of the Certified Center Program and the expansion of professional educational opportunities for affiliated staff. Gilbert thanked the attendees for their ongoing efforts to empower people with Lou Gehrig's Disease and their families to live fuller lives, and confirmed The Association's commitment to the vision of "creating a world without ALS."



From left to right: Steve Good, Director of Communications and Iron Phi, Phi Delta Theta Fraternity; Jane Gilbert, The ALS Association President and CEO; Bob Biggs, Executive Vice President, Phi Delta Theta Fraternity; and Chris Brussels, CEO, The Hill Group (who also serves on the General Council of Phi Delta Theta Fraternity and the Board of Trustees for The Association)

PHI DELTA THETA FRATERNITY A Brotherhood of ALS Philanthropists

By Liz Hall

Phi Delta Theta International Fraternity has had a long tenured relationship with the ALS community and for more than a decade has supported The ALS Association as its national philanthropy in the United States. Through the support of Phi Delta Theta's undergraduate and alumni members, the fraternity has contributed hundreds of thousands of dollars to support research and local programs.

In February, The ALS Association presented Phi Delta Theta with the Partnership for Success Award. This award recognizes those who advance the mission and vision of The ALS Association through exemplary partnership and collaborative efforts to increase the capacity of our organization to serve people with Lou Gehrig's Disease.

Phi Delta Theta Executive Vice President Bob Biggs accepted the award and shared, "We are honored to receive this recognition, and on behalf of our 175,000 alumni and 11,500 students at 175 Phi Delta Theta chapters across North America, we share your passion and dedication to one day finding the cause and cure for ALS. We look forward to continuing to grow the relationship between The ALS Association and Lou Gehrig's fraternity, Phi Delta Theta."

In 2010, Phi Delta Theta launched a new fundraising initiative—the Iron Phi program. In just two years, this program has raised more than \$150,000 for ALS research and continues to grow in participation.

"We've only scratched the surface of this partnership between Phi Delta Theta and The ALS Association," said Steve Good, Director of Communications and Iron Phi. "We will continue to connect our members to the cause and further educate them about Lou Gehrig's Disease. We want to help find a cure for this horrible disease."

To become an Iron Phi, members of Phi Delta Theta must complete an athletic endeavor of their choice and raise \$1,000. In this way, the program not only raises important funds for ALS research, but also leads to personal achievement in strength and wellness. More information about the Iron Phi program can be found at www.ironphi.org.

"We greatly appreciate Phi Delta Theta for continuing to stand strong in the fight against Lou Gehrig's Disease and look forward to continued partnership to find the cause and cure for ALS," said Jane Gilbert, President and CEO of The ALS Association.

The bond between mother and daughter transcends time, distance and death. As the years passed, the grief I felt when Mom died changed, with the desperate sadness gradually replaced by a dull ache and emptiness on those early Saturday mornings when I wished I could call her.



Gradually, in the time since she died (October of 1998), I've had fewer opportunities to talk about Mom. Most have been related to her having had ALS. It felt like the disease was defining her—not the way I wanted to remember my mother. A long-standing desire to create a video compilation about Mom for her three grandsons, combined with my husband, Peter, and I wanting to do something ambitious for The ALS Association, resulted in our establishing a Promise Fund in Mom's memory.

The ALS Patient and Family Care Fund, Honoring Norma Jean (Ray) Fruchey, Evergreen Chapter was launched at the Seattle ALS Luncheon in April 2012. Creating our Promise Fund served several purposes:

- **Help others.** Mom loved people—she never met a stranger (and when she did, she might invite them home to dinner). It's appropriate that this fund would benefit ALS patients and families served by the Evergreen Chapter.
- **Revisit and share our memories of Mom.** Watching old videos, creating our own video montage, looking through family photos, writing about Mom and listening to her friends' stories brought back wonderful memories of her.



Norma and Cheri circa 1962

Making a Promise

By Cheri Kopp

She's the focus, not ALS. Now we can share those memories with others through the site that The ALS Association created and maintains for us.

- **Rekindle our ALS fundraising.** In the first year, our generous friends joined us in contributing more than \$10,000 towards our five-year goal of \$25,000. We appreciate that our friends and family have given directly to the fund and have supported our efforts at local ALS fundraising events. Spending time remembering Mom as we created the site contents, especially the video, was meaningful and might have been reward enough for me. It's a bonus to be able to help others in the process.

Over time, I hope her grandsons (who never knew her) and Mom's relatives and friends will visit and revisit our site. I can imagine Promise Fund sites becoming places of pilgrimage on special days like birthdays, Mother's Day and anniversaries.

Please consider creating your own Promise Fund. Regardless of what moves you—care services, research, legislative advocacy or unrestricted support of operations—The ALS Association can help you create a fund that honors your passion and your loved one. For examples, visit www.ALSPromise.org

For me, ALS isn't Lou Gehrig's Disease; it will always be Norma Fruchey's disease. I can't help Mom any more, but I can try to help others coping with ALS.

Cheri Kopp is an artist/blogger/consultant and career coach. She and her husband, Peter, live in Seattle, Wash. To read more about her mother, visit their Promise Fund site, www.alsa.org/NormaFruchey, or check out Cheri's blog, www.cherikopp.com/blog/category/mom



Promise Fund tribute to Norma Jean (Ray) Fruchey

Create an Enduring Tribute to Someone You Love

As Cheri and her husband discovered, the Promise Fund can be a meaningful way to share treasured memories with loved ones and generations to come. Stories, photos, videos and audio tributes are permanently captured and artfully presented on a customized web page. You can create your own Promise Fund through a gift of \$25,000 or more, made over a period of up to five years. For more information, please contact your local chapter or Karen Starleaf, director donor relations, at kstarleaf@alsa-national.org or (818) 587-2211.



Visit www.ALSPromise.org



Making a Difference in ALS Research

By Pat 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 can help doctors and scientists learn more as they work to find the cause, treatment and cure.

Nobody knows what causes ALS, how it can be prevented or treated—or even how many people are living with ALS in the United States. So in 2008, Congress passed the ALS Registry Act, which allowed for the creation of the National ALS Registry to help find answers. Operated by the Agency for Toxic Substances and Disease Registry, the registry empowers people with ALS to provide information about their disease that can help researchers unlock the mysteries of ALS. By enrolling in the registry, people with ALS can provide information on possible risk factors leading to the disease, such as occupational and family history, lifestyle and military service among others, which can make advances in research possible. This information also will allow the scientific community to measure the true impact of ALS on the nation—how many people have the disease.

In addition to collecting key information that can help find the cause of the disease and improve care for people living with it, the registry can be an important resource for people with ALS and their families. The registry website, www.cdc.gov/als, includes tools to help people locate services in their community and the registry has a clinical research notification system to inform people with ALS about new clinical trials in which they may be eligible to participate.

But the power of the registry to make a difference depends in part on people with ALS themselves.

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

ASSISTIVE TECHNOLOGY

Empowering People with Lou Gehrig's Disease

By Stephanie Dufner

Today's technology enables people with ALS to remain connected with family and friends, even if they cannot speak or use their hands to access a computer. Devices ranging from letter boards to electronic eye-gaze units allow those with the disease to remain active participants in their own lives.

"Communication is linked to humanity," said Alisa Brownlee, Assistive Technology Practitioner (ATP) of The ALS Association's Greater Philadelphia Chapter.

Brownlee, who also consults with The Association's National Office, commented that assistive technology (AT) devices have evolved since their inception more than 50 years ago. Early operators utilized AT instruments that were "slow, heavy and cumbersome," Brownlee said. Lighter—and more agile and portable—devices such as the iPad® allow people with ALS to easily communicate with others in their community, friends and loved ones.

"The iPad has revolutionized the field of assistive technology," Brownlee said. She stated that some with ALS won't use AT devices as they view them as "giving into" the disease. Brownlee, however, has seen that employing these instruments can be motivational and shows that a person "has a willingness to overcome an obstacle," with that hurdle being ALS.

"The iPad is mainstream," she said. "Nobody looks at it as being different." The device is lightweight, portable and

does not require much training. People with ALS and their caregivers are often overwhelmed, and adding a complex communication system can add additional stress to their relationship. The iPad is easy to learn and use, and most people enjoy the device's additional features as well as its communication apps.

There are still a significant number of people with ALS who cannot use the iPad and utilize insurance-funded devices, eye-gaze units (devices controlled by movement of the user's eyes) or low-technology methods for communication.

Letter boards or picture boards are critical for those that have communication difficulties—even if they have an electronic device. Devices can break, electricity can be disrupted or other events may happen that prevent people from using an electronic device. Letter boards can be obtained for free at <http://www.alsphiladelphia.org/page.aspx?pid=933>.

"Technology empowers people," Brownlee said.

People with ALS can use it to play online games, send emails to family and friends or speak with their caregivers.

"Technology gives people their independence."



Alisa Brownlee



Kathleen Kenny from Lakewood, N.J., using Boogie Board® provided by the Greater Philadelphia Chapter

You can follow Brownlee on Twitter through her handle, @ALSAssistiveTec. She also frequently hosts webinars for The Association's Care Services Department and oversees a blog, *ALS Assistive Technology* at www.alsassistivetechology.blogspot.com.

A FARMER'S WIFE CREATES A Legacy of Hope

By Katie Sweeney



Doris and Reynold Horner

Doris Horner describes her late husband, Reynold "Pat" Horner, as "just one of those behind-the-scenes good guys."

"Family was extremely important to him," said Doris, 81, who recently established a charitable gift annuity for The ALS Association. "He enjoyed the wide-open spaces and farming—that was his life."

Both from Illinois farming towns, Doris and Pat met through a mutual friend and married in 1952. They settled on Pat's family farm in northwestern Illinois and raised a son, Mark, and a daughter, Ann, who eventually became a full colonel in the U.S. Army.

Even into his 60s, Pat was still active and enjoying the farming life, with Mark at his side. But in late 1994, he began having trouble lifting the front of his foot—a condition called "drop foot." A local doctor diagnosed him with ALS after just two appointments.

"I remembered the Lou Gehrig story, but I had never known anyone with ALS," Doris said. "I couldn't believe it. It was very hard to accept at first."

Their small community rallied around them, with friends coming by often to help and to play cards. One friend even built a special card

holder for Pat. Meanwhile, Mark took over the farm and helped his mother care for Pat at home.

After her husband's death in 2000, at the age of 71, Doris learned about The ALS Association and began making annual donations. But earlier this year, she decided she wanted to do something more and established a charitable gift annuity, which provides Doris with guaranteed income for life in exchange for her gift of cash or stock.

"It just seemed like the best way to go," she explained simply. "As the saying goes, 'I'm not

rich, but I'm not a pauper, and I had some money I thought I could make useful to support the fight against ALS."

Doris still lives on the farm where she and Pat spent their lives, and she keeps busy playing piano, helping with music contests at local schools and serving as a part-time organist at her church. She has three grandchildren and one great-grandchild.

"ALS is such a devastating disease; we need to find a solution for it," she said. "It feels good to know that I'm doing something to move that effort forward."

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	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 connection with any gift.

For more information or a no obligation proposal,
call 1-888-949-2577 or email gifiplanning@alsa-national.org

Walk to Defeat ALS® Brings Hope to Thousands Living with ALS

By Cathryn Savino

The Walk to Defeat ALS is The ALS Association's largest fundraising campaign and has raised \$21.7 million through 170 events in 45 states. More than just a fundraising event, the Walk brings hope and encouragement to those battling this disease.

One of those people is Cathy Miller of Old Westbury, N.Y. She has participated in the Long Island Walk to Defeat ALS for the past eight years as a team captain. Her team, "For the Love of Jemma," is the top fundraising team in the country, raising more than \$111,000 in 2012, for a total of \$900,000 since 2004. Miller formed this team in honor of her cousin, Jemma, who has been battling this disease for nine years. In fact, her fundraising efforts, and the efforts of thousands of others, catapulted the Greater New York Chapter to raise more than \$2 million in 2012 for local care services, research and public policy.

"More than 120,000 people participate in the Walk to Defeat ALS each year," said Heather McDonald, National Director of the Walk to Defeat ALS program. "Together, we are making a difference in the fight against ALS. We are making progress with accelerated research studies, advanced ALS clinics and enhanced care services chapters provide to families battling this disease."

8. Friends and family members of those battling ALS raise more than 75 percent of all Walk revenue. They do this through the online participant center, letter-writing campaigns, a Facebook application and the hosting of small community events like fashion shows, bake sales or car washes. The dedication and passion for fundraising for ALS is an inspiration, and it is making the difference in the battle against Lou Gehrig's Disease.

You, too, can be part of this year's Walk to Defeat ALS. The season, which kicked off in March, continues with walks held across the country through November. To learn more and register for a Walk near you, visit www.walktodefataals.org. Also, view our new public service announcement at <http://www.youtube.com/user/thealsassociation?feature=mhee>.



For the Love of Jemma Walk Team

ALS Association

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ALS Athlete

Continued from page 2
stones as close to the center of the rings as possible.

A natural athlete, Cummins immediately showed a real aptitude for curling, which requires a great deal of precision, strength and endurance. Her talent caught the eyes of the U.S. Paralympic team coaches.

Within months of taking up the sport, she qualified for the U.S. Paralympic wheelchair curling team. Cummins will compete on behalf of the United States in Sochi, Russia, in March of 2014.

Cummins is only the second athlete with ALS to have been selected for the U.S. Paralympic team; the first being Nick Scandone, a sailor who competed in the 2008 Paralympics in Beijing. Given the rapid progression of the disease, it is difficult to predict whether an athlete with ALS will be able to compete several months out, and the team coaches were naturally hesitant.

"They asked me why they should invest their time and the team's money in someone who might not be able to compete when it



Cathy Cummins

came time," she recalled. "I told them that I don't know what the future holds, but that while I am able to compete, I would be the best athlete they'd ever seen," she said.

ALS Association Oregon and SW Washington Chapter President Lance Christian said that Cummins has truly been an inspiration to others who have been diagnosed with ALS. "She has shown that you can continue to have a good life, even if you are living with ALS."

Cummins appreciates the support of the chapter and emphasized the need to support The ALS Association's work to find treatments and a cure for ALS.

Last fall, Cummins encouraged the chapter to host its first Bike Ride to Defeat ALS, which raised more than \$100,000 and will become an annual event. Having easily finished 50-mile rides in the past, Cummins talked about the 25-mile chapter ride. "My team helped me over the finish line by tying ropes to my recumbent tricycle."

When asked about her plans for the future, Cummins indicated that she plans to remain active as long as her body will allow, saying, "It's all downhill if you aren't going uphill."