A Mile in ALS Shoes, by Bo Stern

People ask me often what it’s like to live with ALS. It’s a brave question because the answers are not very pleasant. But it’s also such a worthy question because understanding how this disease impacts those who suffer from it creates empathy which is so valuable; it carries us into another person’s world and allows us to understand what they’re feeling and how they’re hurting. As I watch my strong husband struggle with things that used to be easy and automatic, I sometimes wish that everyone could see life from his perspective.

Empathy isn’t the same as sympathy. Sympathy means we feel sorry for people, empathy means we work to understand and identify with their pain. Empathy isn’t always easy to squeeze into our busy and difficult lives, but it’s worth it. It makes us more human in all the ways that matter and – in the search for a cure for ALS – empathy is our most effective motivator.

If you would like to experience just a tiny corner of an ALS life, I have a list of Empathetic Experiences for you. These are things you can do to walk for just a mile in ALS shoes. If you try one, take a little time at the end to consider that people actually living with the disease have a million miles more to go.

1. Pick up a 10-pound weight. Now imagine it’s your fork and move it from your plate to your mouth repeatedly without shaking.

2. Sit in a chair for just 15 minutes moving nothing but your eyes. Nothing. No speaking, no scratching your nose, no shifting your weight, no changing the channel on the television, no computer work. Only your eyes. As you sit, imagine: this is your life. Your only life.

3. Borrow a wheelchair or power scooter and try to maneuver quickly through the aisles at Walmart, without speaking. Note the way people react to you.

4. Strap 25 pounds to your forearm. Now, adjust your rearview mirror.

5. Using none of your own muscles, have your spouse or child or friend get you dressed and brush your teeth. Write down some of the feelings you have being cared for in this way.

6. Before you eat your next meal, take a good, long look at the food. Inhale deeply and appreciate the aroma. Now, imagine never being able to taste that – or any other food – for the rest of your life.

7. Put two large marshmallows in your mouth and have a conversation with your friends. How many times must you repeat yourself? How does this make you feel?

8. Go to bed and stay in one position for as long as you possibly can, moving nothing.

9. Strap weights to your ankles and climb a flight of stairs, taking two at a time. That’s the kind of strength it takes for someone with ALS to tackle the stairs on a good day.

10. Install a text-to-speech app on your phone or iPad and use it exclusively to communicate for one day.

And to my friends living with ALS: please give us more ideas and help us move into your world for a bit. We want to help make your lives rich and full and I’m not sure we can do that without at least a basic understanding of what you are facing. I think I speak for many when I say: you are superheroes and we are in awe. **Reprinted from bostern.com**
Welcome Maggie!

We are happy to welcome Maggie Pimm to our team as our new Bookkeeper and Operations Coordinator. Maggie has extensive experience with bookkeeping, database systems, and office coordination. Maggie is married with three cats. She enjoys bike riding, photography, reading, and a wide variety of music. Her most unusual leisure activity is Autocross. She took first place in her class last season.

Marilyn Adair, Judy Austin, Jim Baker, George Butcher, Judy Carmody, John Condon, Patrick Contert, Peggy Dixon, Jonnie Downey, Glenda Epperly, John Groman, Tom Guernsey, Pamela Hansen, Gerald Helms, Juanita Horst, Joanie Johnson, Frances Kennedy, Jack Lowman, Mary Jo Piccaccia, Rebecca Richardson, Ronald Richter, Ronald Romadka, Grace Schimke, Douglas Strutz, Cynthia Tangrurd, Hoa Tran, Duane Wallace, Paul West, Douglas Willburn, Bob Winter

In recognition of those who have recently lost their battle with ALS, we remember their courage in living and keep their spirits alive in our memories and hearts. We will continue the fight in their honor.

June 12th, 2012 – October 12th, 2012

This list is based on chapter notifications; please notify us of any omissions or errors.

We send our sympathy and continued support to those families and friends who have lost someone to ALS or are currently living with the disease. We extend thanks to those who have designated our chapter for donations.

Donations, outside of event contributions, have been made in memory of and in honor of the following people:

Ronald Anderson, Judy Austin, Jim Baker, Bonnie Burdell, Barbara Collins, John Condon, Patrick Contert, Lonna Gustavson, Gerald Helms, Nancy Ann Molland, Ronald Richter, Jo Anne Ridley, Barbara Roth, Grace Schimke, Cynthia Tangrurd, Hoa Tran, Steve White, Linda Wind

Contributions received support care services, public and professional education, public policy, and research. Upon receipt of the gift, a thank you letter is sent to the donor and an acknowledgement of the gift is sent to the person or family designated.

The ALS Association has made every effort to ensure the memorials, tributes, and donations are properly recognized and correctly spelled. We apologize for any errors and ask you to call us at 1-800-681-9851 with corrections so our records can be changed and updated.

SAVE THE DATES FOR 2013
MARCH 9, 2013 Annual Dinner and Auction Gala
APRIL 13, 2013 Ski to Defeat ALS
JULY 13, 2013 Ride to Defeat ALS
SEPTEMBER 2013 Walk to Defeat ALS®
NW Oregon & SW Washington

Our Services Staff have been hard at work assisting families living with ALS in navigating insurance and healthcare choices, loaning families needed medical equipment, providing respite care, leading support groups, participating in The Providence ALS Center and more. One of the most meaningful things we do is to make home visits with newly diagnosed families and help people find their bearings and plan for the future. This summer our Portland-based staff has visited with newly diagnosed families from Washougal to Silverton and spots in between.

Services Coordinator Sarah Greenstein returned to work in mid-August with a heart full of gratitude after a summer of family bonding following the birth of her third daughter, Sami Kaela, in late May. Sami arrived just a few weeks after her husband, Hayden, was diagnosed with ALS for the youngest Walk participant award at the Portland Walk to Defeat ALS on September 30th. This year’s sunshine and the tangible positive energy in honor and in memory of all our PALS was something special.

Our Yamhill County Support group will celebrate its one year anniversary on October 11th at the McMinnville Community Center. Thank you to our families from beautiful Yamhill County for providing each other with much needed support and a sense of community that is so important in one’s journey with ALS.

An important reminder for all Medicare recipients! October 15-December 7 is the annual open enrollment period for Medicare to add or make changes to supplement plans. Those adding an Advantage plan for the first time can choose to have their plan take effect on the first day of the month following the enrollment. If changing a plan, the new plan will take effect January 1, 2013. We will welcome Janet Bowman, the SHIBA (Senior Health Insurance Benefit Assistance) and Medicare Coordinator from Multnomah County’s Office of Aging and Disability to invite all family caregivers to our monthly Family Caregiver Support Group on October 17th. You can contact Nancy and Liz Mullen from NORCO Medical continues to be a valuable resource for us managing our loan closet and delivering much needed equipment in our area so we are very sad to have had to say goodbye to Ruth Little from NORCO. She was wonderful to work with and it was obvious how meaningful managing the loan closet was for her. David Hamilton is now our main contact with Norco and the Loan Closet. David also manages the loan closet was for her! David Hamilton is now our main contact with Norco and the Loan Closet. David also manages the loan closet and helping people living with ALS acquire the equipment, services and support they need. Support groups continue to bring people together to share and learn. Speaker Kathy Temes, occupational therapist discussed alternate ways to accomplish tasks of daily living, and Susan Hearn, health educator explained the importance of Oregon’s Mobility Access Options for loaning an adapted van to the Allen family on walk day. In Eugene, David and Pat Collins enlised the Olive Garden for tasty post-walk nourishment.

November is National Caregiver Month, a time to recognize the dedication and commitment of family members who provide essential care to loved ones with ALS. Southern Oregon caregivers will be treated to a luncheon on November 6th at Applebee’s in Medford, while caregivers in the Eugene/Springfield area will be treated to dinner at Papa’s Pizza. The ALS Association is dedicated to assisting family caregivers who strive every day to meet needs and enhance the quality of life for their loved ones.

We receive on-going support from volunteers, such as Stewart Smith, Kyle Wisdom and Betty Lou Loe, who collected and stored ramp materials. Our community partners at the Medford Eagles Lodge, Betty Johnson and Rae Eatherton, host a monthly luncheon and produce an annual fundraiser for PALS’ out-of-pocket expenses. And, as always, we appreciate Garry Flaim of Care Medical for managing our loan closet. As we approach 2013, we salute the team work and generosity of all who share our ALS community.

Regional Services Coordinator Gail Galaher has been busy raising community awareness and helping people living with ALS acquire the equipment, services and support they need. Support groups continue to bring people together to share and learn. Speaker Kathy Temes, occupational therapist discussed alternate ways to accomplish tasks of daily living, and Susan Hearn, health educator explained the importance of Oregon’s Mobility Access Options for loaning an adapted van to the Allen family on walk day. In Eugene, David and Pat Collins enlisted the Olive Garden for tasty post-walk nourishment.

November is also host to Veteran’s Day. As many of us know, veterans are twice as likely as the general population to be diagnosed with ALS. As a service connected disease, there are many specific benefits available to veterans living with ALS. Our ongoing collaboration with Paralyzed Veterans of America helps our veterans connect with these benefits and the Veteran’s Administration system. We are there to help people learn to help their loved one live with the disease day in and day out . . . not to mention the ingenuity, creativity, patience and persistence they must demonstrate. In addition to the links on our website during the month of November focusing on care giving tips and resources, our respite care fund, and taking extra time out to thank the caregivers in our community, we would like to invite all family caregivers to our monthly Family Caregiver Support Group on Thursday afternoon, November 15th from 4:00-5:30pm at Legacy Meridian Park in the Health Education Building. We are there to support you with light refreshments and special tokens of acknowledgement.

An important reminder for all Medicare recipients! October 15-December 7 is the annual open enrollment period for Medicare to add or make changes to supplement plans.

This information is vital for long term planning and November is also host to Veteran’s Day. As many of us know, veterans are twice as likely as the general population to be diagnosed with ALS. As a service connected disease, there are many specific benefits available to veterans living with ALS. Our ongoing collaboration with Paralyzed Veterans of America helps our veterans connect with these benefits and the Veteran’s Administration system. We are there to help people learn to help their loved one live with the disease day in and day out . . . not to mention the ingenuity, creativity, patience and persistence they must demonstrate. In addition to the links on our website during the month of November focusing on care giving tips and resources, our respite care fund, and taking extra time out to thank the caregivers in our community, we would like to invite all family caregivers to our monthly Family Caregiver Support Group on Thursday afternoon, November 15th from 4:00-5:30pm at Legacy Meridian Park in the Health Education Building. We are there to support you with light refreshments and special tokens of acknowledgement.

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The monthly ALS support group continues to meet the second Wednesday of every month at 11:30 am in various conference rooms at St. Charles Medical Center in Bend. This summer the support group welcomed Nancy Crawford and Liz Mullen from the Oregon Aging and Peoples with Disabilities Program office. Nancy and Liz spent time describing the in-home care Assistance Program which provides as well as answering questions about financial eligibility for those services.

Betsy has been doing home visits, phone calls, letters as she has been getting more familiar with the diverse needs and challenges that local people living with ALS face. Betsy has also been participating in the ALS Clinic at St. Charles Medical Center in the social work role discussing insurance needs, addressing financial issues, identifying care giving challenges and respite opportunities as well as providing emotional support.

An important reminder for all Medicare recipients! October 15-December 7 is the annual open enrollment period for Medicare to add or make changes to supplement plans.

In July, Betsy Paige, LMSW took over the role of the Regional Services Coordinator for Central Oregon and has been working hard to fill the shoes of Kathleen Rong who served the ALS community for over 5 years. Betsy has been busy this summer building relationships within the ALS community as well as with the many community partners of Central Oregon.
Researchers Find Genetic Region Influencing Age at Which People Develop ALS

The ALS Association has announced that an international consortium of researchers it convened and funded has identified a region on chromosome 1 that strongly influences the age at which an individual develops amyotrophic lateral sclerosis (ALS). For the first time, scientists have found that people with ALS, who have a specific genetic signature within this region on chromosome 1, had an age of onset that is approximately two-and-a-half years earlier than those without it. The study was funded in part by The ALS Association and published today in Neurobiology of Aging.

“The discovery of a region or genetic center on chromosome 1 that influences the age at which a person develops ALS is critically important for understanding the disease process,” said Lucie Brujin, Ph.D., Chief Scientist for The ALS Association. “There are many pathways that lead to ALS, and this new discovery suggests that there may be common factors to all of these pathways, which enable researchers to develop new treatments that help slow or stop the disease.”

The study examined the DNA from more than 4,000 ALS patients and 5,000 control subjects of Caucasian origin. Researchers found that those individuals with a specific genetic signature within a region on chromosome 1 had an age of onset approximately two-and-a-half years earlier (56.5-years-old) than those without the genetic signature (59-years-old). In addition, the study confirmed genetic risks for ALS and suggested novel regions that merit more study.

“Although a 2.5 year delay in the onset of ALS may not seem large, it is very important as it is comparable to the average survival time once diagnosed with ALS. The fact that it is associated with such a significant change in the age of ALS onset hints at a role in the rate of progression, maybe in accelerating the disease process,” said Dr. Langefeld. “The consistency of this locus’ effect across the 13 Caucasian cohorts is remarkable and underscores its broad impact.”

This new research was conducted by the International Consortium on Amyotrophic Lateral Sclerosis Genetics (ALSGEN), and analyzed by Carl Langefeld, Ph.D., of Wake Forest Baptist Medical Center in Winston-Salem, North Carolina. This work was supported by The ALS Association, the Packard Center for ALS Research at Johns Hopkins University, and Microsoft Research. This work was also funded in part by the Intramural Research Program of the NIA and NINDS. Analysis and computing resources were provided by the Wake Forest School of Medicine Center for Public Health Genomics.

New Research Shows Link Between ALS and Another Motor Neuron Disease

A study published in the September 28 edition of Cell Reports indicates that ALS and another disease involving motor neurons called spinal muscular atrophy (SMA) are linked at the molecular level. The research, led by Robin Reed, Ph.D., Professor of Cell Biology at Harvard Medical School in Boston, Massachusetts, offers new insights into the disease process in both diseases.

ALS affects adults; SMA affects children. Both diseases are caused by the death of motor neurons, cells that control muscle and allow movement. One cause of ALS is a mutation in a gene called FUS. SMA is caused by mutation in a gene called SMN. In this new study, the team, which involved scientists from the United States, the United Kingdom and China, investigated the interactions of the FUS protein with the SMN protein. They found that the two proteins physically linked up in the cell nucleus. That discovery was the first indication that a protein involved in ALS interacts with the protein involved in SMA. The finding suggests that this pathway may be disrupted in both diseases.

“This new finding will help accelerate the understanding of the causes of ALS because scientists have now identified a critical link between two very different diseases that both cause the degeneration of motor neurons. That link is likely to play an important role in the ALS disease pathway,” said The ALS Association Chief Scientist, Lucie Brujin, Ph.D.

The ALS Association contributed funding to support two of the researchers involved in the study through its Translational Research Advancing Therapies for ALS (TREAT ALS™) program. The program supports a diverse portfolio of research every year in order to find treatments and a cure for Lou Gehrig’s Disease.

Study Shows NFL Players Four Times More Likely to Die from ALS; NFL Donates $30 Million to NIH for Research on Brain Injuries

According to a new study published in Neurology®, the medical journal of the American Academy of Neurology, National Football League (NFL) players may be at higher risk of death from diseases that damage brain cells. This news came on the same day as the NFL announced it was donating $30 million to the National Institutes of Health to fund research into brain injuries and other medical issues; this represents the largest donation in NFL history.

The study, which was supported by the National Institute for Occupational Safety and Health, and conducted by Everett J. Lehman, M.S., with the National Institute for Occupational Safety and Health in Cincinnati, included nearly 3,500 former players in the National Football League, who all played at least five seasons from 1959-1988. About ten percent (or 334) of the participants had already passed away.

“Researchers looked at death certificates of the deceased players and determined that a player’s risk of death from diseases that damage brain cells was almost three times that of the general population, and a player’s risk of death from ALS or Alzheimer’s was almost four times higher than the general population.”

“Although it is unclear exactly what causes this heightened risk in the NFL, one factor that may be shared with ALS and Alzheimer’s disease is the brain injury that occurs as a result of repeated blows to the head,” said Lucie Brujin, Ph.D., Chief Scientist for The ALS Association. “More study with a greater number of participants will be needed to fully understand this relationship. Understanding how injury may trigger a long-term degenerative process may shed light on the mechanisms of ALS from other causes as well. We are hopeful that the NFL’s significant commitment to research will lead to finding a cure for ALS and to discovering treatments to help people live longer, fuller lives.”

Honoring our veterans...

For unknown reasons, people who serve in the military are twice as likely to develop ALS as those in the general population. This Veterans Day, honor a veteran with ALS on The ALS Association’s Wall of Honor at www.alsa.org/wallofhonor, which will help raise awareness and support in the fight against this devastating disease.

Rilutek is the only FDA-approved drug available to treat ALS. It inhibits glutamate release, and prolongs life approximately three months. Riluzole is the generic name of Rilutek. It can be very costly to take this drug.

Rilutek can be provided for free if a patient falls <250% of federal poverty level. Proof required, i.e. tax returns, SS statement, etc.

Patients can receive up to 50% of out-of-pocket expenses (up to $100/mo or $1200/yr). Patients on Medicare, Medicaid, or government funded insurance are not eligible. Private insurance or no insurance is okay and no income level restriction applies.

Vouchers are available for 7 day trial or 14 free tabs. Many people living with ALS don’t want to spend money on full month supply if there is a possibility they won’t tolerate the medication.

Contact us if you would like to learn more about these options. Reach out to your local services coordinator or contact Lance Christian at 800-681-9851 ext 1.
The Caregiver’s Role in Supporting Communication

Augmentative and Alternative Communication (AAC) systems are often recommended for people with ALS (PALS) when they begin to experience changes in their ability to communicate effectively. Typical discussion usually addresses details about equipment, helpful methods and strategies, locating funding sources, programming devices, and providing technical support needs. However, many of our PALS also depend on their caregiver to support their communication needs. Therefore, this article discusses the support skills for those caregivers who may be new to the world of AAC.

Observe
Listening for changes in communication. A change in speech or voice is a common initial symptom that many PALS and their families notice. Symptoms may include slurred or unclear speech, a tongue that seems or feels thick, or a softer than normal voice. Whatever the symptom or feeling, it is important to listen and communicate with each other regarding these changes. An honest conversation could help identify speech changes early on, which is crucial for expanding options and intervention choices. One option, voice banking, is the process of recording one’s voice and saving it to the computer. The recordings could then be transferred and programmed onto a computerized communication device should the PALS wish to access them in the future.

Watch for changes in activities. Have you noticed your PALS complaining of changes, or not as active in their favorite activities or hobbies? Changes in access, such as not being able to type as easily, or not being able to hold a phone to their ear, are often able to be resolved with assistive technology. There are many tools and strategies designed to help PALS continue to do the things they enjoy and maintain their quality of life.

Take note - literally! Your Speech Language Pathologist would find a list of these changes to be quite a helpful tool to reference during a clinic or home visit. The changes that you notice might be small, but could very well be the most meaningful areas to be concerned with. If you notice any changes, take a note, and perhaps would have added something along the lines of, “that woman needed to get hit with the get-over-herself stick.”

Support
Set up for success. Once the appropriate systems have been established, try to learn about proper positioning and set-up for each new piece of equipment or strategy. If you are mounting a communication device, learn about the distance and angles required to enable your PALS’ optimal access point. Does the equipment seem like it is working right? If needed, contact your Speech Language Pathologist or the tech support call center for answers. Don’t worry—even if you are not a tech-savvy person, most companies have tech support systems that can remotely problem-solve device programming issues, provided that you are connected to the internet.

Promote independence. The goal of using these services is to help PALS communicate and actively participate in their own lives. Enjoying the same activities or hobbies, maintaining their role in the family, and insuring they remain connected within their community all depends on having the right support. Once the equipment or strategies are in place, support your loved one by encouraging them to use the systems, gain independence, and continue being themselves.

Take good care. Remember to take care of yourself too! Take time to continue to do the things you enjoy, and give yourself breaks whenever possible. Establish alert systems like a Lifeline to support your loved ones safety when you leave the house. Use a wireless doorbell or walkie-talkie system to continue working outside in the yard or garage. Take advantage of the ALS Association respite care services, if possible.

Advocate
Reach out for support. Once changes have been identified, it is important to reach out and communicate. Caregivers are often depended upon to alert the healthcare team when additional support is needed for the PALS, especially if they have experienced changes in their communication abilities. Initiating conversations, supporting the PALS with communicating to their audience, and following-through on the issues may rest primarily on the caregiver’s shoulders.

Actively participate. When discussing AAC and assistive technology with your Speech Language Pathologist, it is important to learn about the equipment, ask questions, and be honest about the topics that are being addressed. Caregivers, you know your loved one best. If they aren’t likely to use the strategy or equipment, it is helpful to communicate that to the professional giving the recommendation. However, many of our PALS also depend on their caregiver to support their communication needs. Therefore, this article discusses the support skills for those caregivers who may be new to the world of AAC.

sometimes it's hard to be the healthy one, by Bo Stern

Oh dear, I just read my own headline and thought about how I would have responded to it two years ago, before I was the only healthy spouse in the house. “Whiner!” I would have thought.

And yet, I feel it nearly every day, when…

I race out the door to work and I know how much Steve misses his job and how difficult it can be for him to find things to do during the day.

The waiter at a restaurant has trouble understanding Steve (restaurants are noisy and Steve's voice is much softer than it used to be) and so I jump in to explain and from that moment on, he directs every question and comment to me and then brings me the bill when the meal is done.

I complain about being busy when I know how much Steve would love to be busy.

I leave to work out or walk the River Trail.

I ask him to pick up milk at the store before remembering that he wouldn’t be able to lift it up to the counter.

I forget that I’m in charge of his laundry now. He’s always done his own laundry.

Our Respite Care Program – Giving Family Caregivers a Break

When someone is diagnosed with ALS, it is not just the person with the diagnosis that is affected. ALS often impacts the lives of family as dramatically as the person with ALS. Spouses, parents, siblings and children of people with ALS can suddenly find themselves as primary caregivers, providing full support to their loved one with ALS.

Our Respite Care Program is available for the use of all people with ALS and their families residing in Oregon and SW Washington regardless of means. Up to $750 is available per family to hire non-family caregivers to give the primary family caregivers a break to rest, relax, enjoy a favorite activity, take a vacation, and recharge their batteries.

For information about accessing the Program, please contact the chapter office at 503-238-5559 ext 1., or toll free 800-681-9851 ext 1.

Thanking our caregivers…

November is National Family Caregivers Month, a time to send a “thank you” to these special individuals for their commitment and support. Send a personalized e-card to a caregiver you know from The ALS Association’s website, www.alsa.org/e-card.
Dear Meagan…

In this issue of The Voice, we’d like to answer some common questions about the Walk to Defeat ALS®. If you have questions that still need to be answered, please let us know. Give us a call at 800.681.9851x2 or email us at walk@alsa-or.org today.

Executive Director Lance Christian talked with Meagan Lancaster, Fundraising Manager, about some common questions and misconceptions about our national signature event.

Lance: Meagan, how did the Walk to Defeat ALS® go this year?

Meagan: Oh, yes! Well this one is easy. The Walk to Defeat ALS® is a fantastic and powerful awareness event, but, it’s a fundraiser. Actually, it’s our largest fundraiser of the year. They’re a great incentive, and by wearing one, you’re throwing the world that you’ve done your part. Plus, we have to order them in August from our national vendor, so this helps us plan appropriately and helps cover our costs.

Lance: But why $25?

Meagan: We feel like $25 is an easy level to hit. The $25 t-shirt minimum was put in place to help each and every participant fundraise. We’re not asking everyone, you’re already over. As you know, our participant fundraisers are the most successful fundraisers.

Meagan: This is a great question. I mean that I can register you and your family over the phone or via email. I can meet with you to brainstorm ideas to engage your friends and family. Want to email your network but not sure what to say? Let’s meet and I can write your appeal for you. Interested in engaging your company? That’s a fun one, too. I can meet with managers to get companies involved. Need help mailing out (or emailing out) your story? We can help with that too. Possibilities are endless and my job is to help people be successful in their fundraising.

Lance: When can we sign up for next year’s Walk to Defeat ALS?%0D%0A

Meagan: We hope to have the websites open in February 2013! We’ve been able to plan change in a jar for a couple months and we’ve earned your shirt. Or even collect instead, ask five friends for just $5 and they’re already over. As you know, our team started on the road to success!

Top 25 teams raise significant funds to support the fight against ALS.

Across our service area of Oregon and SW Washington, these teams, led by passionate and dedicated team captains, pulled out all the stops. The following teams were ranked as our top 25 fundraising teams. Be sure to check out our Spring edition of The Voice for the top teams per walk location.

Each ounce of awareness and every penny earned by all walkers ensures that our services are here to stay as we move into 2013 and beyond.

Team Krye - $24,375 – Portland Metro
Team Arne’s Warriors - $21,790 – Portland Metro
Team Stern - $14,240 – Central Oregon
Steve’s Wobbly Knees - $12,445 – Portland Metro
Team MJ - $12,365 – Portland Metro
Swissline - $11,945 – Southern Oregon
BB - $11,715 – Portland Metro
Freddy’s Walkers - $11,242 – Portland Metro
Team Crawford - $10,581.05 – Portland Metro
Willamette Valley – Walkers in the Talk - $10,240.20 – Portland Metro
Dor’s Wing Walkers - $9,690 – Southwest WA
Laurens’ Lions - $9,375 – State Capitol
For the Love of Eric - $7,900 – Southwest WA
Gang Grenere - $7,570 – Portland Metro
Streitz Your Stuff - $7,525.45 – Portland Metro
Shannon’s Angels - $6,668.13 – State Capitol
Rani’s Fans - $6,600 – Southwest WA
Walk for a Cure - $6,560 – Portland Metro
Willburn’s Walkers - $6,375– Portland Metro
Honey Budgers - $6,025 – Portland Metro
Jerry’s Helmstones - $5,965 – Southwest WA
Brian’s Pillars of Support - $5,868.07 – Southwest WA
Walkers in Memory of Jonn Keesling - $5,764.40 – Willamette Valley
Red Wigs - $5,745 – Portland Metro
Team MasterCare - $5,615 – Portland Metro

The 2012 Walk to Defeat ALS® Finding power. Finding purpose. Finding a community that understands exactly what it’s all about.

Throughout the month of September, across Oregon and SW Washington, people banded together for one reason. Support. Support can come from a variety of avenues – financial support, emotional support, and even supporting the cause by raising much-needed awareness amongst the general public. Yet, in the end, it all means the same thing. It means that through our different journeys with ALS, we are never, ever alone.

The Walk to Defeat ALS® is always full of hugs, smiles, tears and laughter. It’s full of families and friends making memories and going the extra step to show just how much we all care. This year was no different. We saw colored wigs. We saw team t-shirts. We saw costume bars and team flags. The spirit of the Walks to Defeat ALS® was out in force with all of the participants.

This year, the Walk to Defeat ALS® brought more than 5,000 participants together in honor and in memory of those whose lives were forever changed by the disease. It brought this same support, hope, and well over half a million dollars directly to The ALS Association Oregon and SW Washington Chapter.

By being part of the Walk to Defeat ALS® as a team captain, participant or donor, you helped create necessary change in our ALS community. For this, we thank you.

Make Your Shot. Make a Difference.

Becky Brockway has been part of the Walk to Defeat ALS® for several years now. Walking each year in honor of her brother, Bob, Becky decided that in 2012, she could do even more. Since Bob is a golf enthusiast, what better way to raise additional funds and show even more support for her brother than organize a golf tournament in his name.

Having never planned a golf tournament before, Becky wasted no time organizing. From finding sponsors, to recruiting players and even setting up a successful dinner and auction portion of the event, Becky was unstoppable. And, her hard work and dedication paid off – The Make Your Shot, Make a Difference tournament raised over $11,000 for Becky’s walk team. Her “labor of love” placed their team in the top five fundraising teams on Walk Day in Portland, Oregon.

“Our first annual golf tournament was so fun to host and because it was a labor of love for my brother Bob, who suffers with the debilitating disease of ALS every day, it was extremely rewarding and fun to do. Our entire family had a role and it gave us something to focus on and do for raising awareness and funds for The ALS Association. We had so much fun!”

Each ounce of awareness and every penny earned by all walkers ensures that our services are here to stay as we move into 2013 and beyond.

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Gang Grenere - $7,570 – Portland Metro
Streitz Your Stuff - $7,525.45 – Portland Metro
Shannon’s Angels - $6,668.13 – State Capitol
Rani’s Fans - $6,600 – Southwest WA
Walk for a Cure - $6,560 – Portland Metro
Willburn’s Walkers - $6,375– Portland Metro
Honey Budgers - $6,025 – Portland Metro
Jerry’s Helmstones - $5,965 – Southwest WA
Brian’s Pillars of Support - $5,868.07 – Southwest WA
Walkers in Memory of Jonn Keesling - $5,764.40 – Willamette Valley
Red Wigs - $5,745 – Portland Metro
Team MasterCare - $5,615 – Portland Metro
Thank you to our 2012 Year-Round Partners: Fred Meyer, Northwest Medical and Wells Fargo
Local businesses support the 2012 Walk to Defeat ALS®

Under the direction of Dave Underitter, Providence Health & Services Chief Officer, Delivery Systems, Oregon, our 2012 Corporate Effort for the Walk to Defeat ALS® season was a SUCCESS!

We thank the following business leaders for their commitment to the fight against ALS.

Together, they have collected well over $70,000 towards our overall goal of raising over $650,000!

Our Walk to Defeat ALS® Sponsors and Partners for 2012

Ensuring all of your fundraising dollars benefit care services, public policy and international ground-breaking research efforts, our sponsors covered the costs of hosting the event. Thank you to the following businesses for their generous support of the 2012 Walk to ALS®

Volunteer Spotlight

Some people volunteer at the Walks to Defeat ALS® to show support for The Association and enjoy the excitement and last fun of Walk Day. There is however a lot of work that goes into preparing for the Walk before it even starts and sometimes it is not nearly as enjoyable.

That is where Mike and Kam Delaney have stepped up in a big way. Every Friday all the supplies for the walk: the pop up tents, the signs, the T-shirts, the snacks and many other miscellaneous items have to be moved from our storage unit in our basement, loaded into the freight elevator, and packed into the van. Mike and Kam Delaney are great at rolling up their sleeves and doing the heavy lifting. Mike has a particular skill in managing to squeeze everything into the van.

Having assistance loading and unloading the van is one of those tasks that turns the task from difficult to easy when one person is doing it to a one hour project.

Volunteers, we thank you!

Thank you to all the individuals who volunteered their time in 2012. Volunteers helped with everything from assembling mailings, making phone calls to setting up events and running errands. Our 2012 volunteers collectively worked over 2,500 hours and worked hard to save us over $45,000 in time and effort!

There are many other individuals that assisted in van loading and unloading throughout the Walk to ALS® last month including Mike Spencer, April Candleria, Jenica Reese and Mike Turner - all of whom are dedicated and excellent volunteers!

AOA Newsletter 2012 – Volume 2, Issue 2

Thank you to our 2012 Year Round Partners: Fred Meyer, Northwest Medical and Wells Fargo
Last year, The Ski to Defeat ALS broke all kinds of records, and we're ready to do it all again. We've set a lofty goal of raising $150,000 – dollars that will directly benefit our local chapter and the families that we serve. It promises to be another unforgettable event. After all, people are still talking about the event last year.

Led by Honorary Chair, Fred Noble, the 2012 Ski to Defeat ALS sold out days before the event. The fundraising goal was met weeks before. This year, we've doubled our capacity and hope to welcome twice as many as 500 ski and snowboard enthusiasts to Mt. Hood Meadows.

Here is what you need to know:
Register today by visiting www.SkitoDefeatALS.org or by calling 800.681.9851x2.
The cost is $75 to register and each participant must fundraise at least $150. Don’t worry – the fundraising is the easy part! We do have a NEW special registration fee of only $25 for Mt. Hood Meadows Season Pass holders.
At the event, you can expect three tasty meals, an awards celebration at the end of the day complete with alcoholic and non-alcoholic beverages (two alcoholic drinks per participant are part of your package), entertainment by Moe Dixon and so much more! We’ll also be tracking your vertical feet, so get as many runs in as you can and take home a travelling trophy!
We encourage you to form a team and invite your friends and family to join you on the slopes.
Finally, through a partnership with Oregon Adaptive Sports (OAS), we would like to invite any person living with ALS to join us as our guest. Oregon Adaptive Sports will have the necessary equipment to accommodate a few runs down the mountain. Last year, nine people with ALS experienced this amazing opportunity! Spots are limited so reserve yours today!
Patty Belcher has been living with ALS since 2010. Prior to the Ski to Defeat ALS, she had never skied or snowboarded. Of her experience she says, “Have no fear! OAS is here for you! They made the experience so fun and easy. I’m so glad I participated and I can’t wait for the 2013 event!”
So, what is holding you back? Learn more and sign up today at www.SkitoDefeatALS.org.

The Inaugural Ride to Defeat ALS was a Success!
On July 14, 2012 hundreds of riders and guests gathered together in Mt. Angel, Oregon for the first ever Oregon Ride to Defeat ALS. With 25 mile, 50 mile and 100 mile challenges, the event delivered picturesque scenery, top-notch rest stops complete with cheerful volunteers and tasty treats, and an overall celebration of thanks, hope and support. The dedicated riders worked together and successfully raised $100,000! In celebration, all participants were treated to some extra fun festivities – a bouncy house, magician, band, and more! We cannot wait for next year’s event. Save the date: July 13, 2013.

Many thanks to our 2012 top performers:
Top Five Fundraising Teams:
Ken’s Kismet - $11,457.33
Team ROAR - $11,075.91
Randy’s Riders - $6,800
The Crank Armstongs - $5,425.45
Guys & Gals Riding for PALS - $5,305

Top Five Fundraising Individuals:
Ken Feldaus - $8,325.33
Ron Zahm - $3,433.34
Susan Cassidy - $3,355
Cathy Cummins - $2,583.33
Doug McClure - $1,965

Much gratitude to the following Ride to Defeat ALS committee members whose efforts, time and connections made our first event such a success!

Scott Cassidy
Susan Cassidy
Tony Halford
Doug McClure
Mark McDaniel
Shad McIlagan
Kate Moore
John Schaffers
Debby Willett
Ken Willett

Gold Sponsor
Expo Booth Sponsor
Rest Stop Sponsors

Thank you to our 2012 Year-Round Partners: Fred Meyer, Northwest Medical and Wells Fargo
Steve and I shared so many wonderful years together. Steve worked for Intel for many years, and later spent his days volunteering at Aloha High School. Tutoring kids in math at the high school was the highlight of his day, and many of the kids looked up to him. He positively impacted so many lives this way.

Steve was, unfortunately, diagnosed with ALS in 2007 and nearly immediately found a community of both friendship and support within The ALS Association. We attended monthly support groups together. Steve was even asked to share his knowledge of business and his forward-thinking, conceptual mind as a member of The Association’s Board of Directors.

He found incredible support leading his Walk to Defeat ALS’ team, Steve’s Wobbly Knees, to be one of the top fundraising and biggest teams in the region. All of this was a silver-lining to his quickly deteriorating condition. Steve lost his voice, tutoring became difficult and he became dependent on his power wheelchair and bi-pap machine. In September of 2010, just before the Walk to Defeat ALS’, Steve passed away.

The ALS Association Oregon and SW Washington Chapter meant so much to Steve and me— not only because of the support we received, but for the friendships that were developed. As Steve once put it, “challenges with ALS are viewed as a shared experience, rather than with pity or sorrow.” We understood firsthand the help and care required to live a good life with ALS, and Steve wanted to help those yet to be diagnosed receive the same level of service.

By leaving a bequest to the chapter of $25,000, Steve did his part in ensuring that the services that we were able to take advantage of remained a stable part of The ALS Association’s mission.

Thank You Home Depot Foundation

This effort is part of Celebration of Service, The Home Depot Foundation’s two-month initiative to do more for U.S. military veterans. During Celebration of Service, The Home Depot associates will complete hundreds of service projects across the country between September 11 and Veteran’s Day to give back to those who have served our nation.

Volunteer projects throughout the day included:

- Painting of homes
- Weatherization of homes to increase energy efficiency
- Optimization of safety and accessibility
- Overall landscaping and maintenance

John Deeming, a dedicated volunteer in Portland, Oregon, has generously offered to provide hands-on support for this effort. He is willing to travel to you or set up a phone call to walk you through the steps, answer any questions, and share information about what this registry will be able to do for the ALS community. His willingness to travel is region wide, not just Portland based.

Visit www.cdc.gov/ALS to sign up today or contact us at info@alsa-or.org or by phone at 503-238-5559 ext 1 to get help.

Update on National ALS Registry!

Every person currently living with ALS can be a crucial part of creating a world without ALS. Every person living with ALS in the United States can self-enroll in the National ALS Registry! The National ALS Registry may be the single largest ALS research project ever created and is designed to identify ALS cases from throughout the entire United States.

Not tech savvy? Need some extra assistance? Support is available.

Claire Whitaker Peterson
Successful Writer for Television Wife and Mother Philanthropist

Join Claire in the fight against ALS by making a legacy gift through your will or living trust. Help us keep hope alive for those battling ALS by supporting our work to eradicate this devastating disease. Please contact our Chapter for more information.

Support the ALS community by participating in our Monthly Giving Circle!

Monthly giving through our chapter’s headquarters offers a convenient way for you to support the important work of our Association in your community throughout the year. Members of our Monthly Giving Circle provide The ALS Association, with a much needed dependable stream of income that we use to provide support groups, find resources for people living with ALS who need them, maintain and grow our medical equipment loan closet and support national and local research efforts — so eventually, there will be no such thing as Lou Gehrig’s Disease.

On a monthly recurrence, your contributions are charged to your credit card, or debited from your checking account, on a specified day of the month that you request. At any time, you may change your gift amount or payment method or cancel your participation.

To sign up, please contact Aubrey McCauley, Development Director, at AubreyMcCauley@alsa-or.org or 800-681-9851 ext 3.
**SUPPORT GROUP SCHEDULE**

**Portland Metro Area**
1st Tues. of every month, 3:00pm - 4:30pm
Providence Portland Medical Center,
Social Room Conference Room
4805 NE Glisan St., Portland, OR
For more information and directions contact: Lance Christian at 503-238-5559 ext 1
In Partnership with the Providence ALS Center. All people with ALS are welcome regardless of where they receive their care.

3rd Thurs. of every month, 4:00pm – 5:30pm
Note: this group is for family caregivers only.
Legacy Meridian Park Hospital,
Health Education Center – Room 106
19300 SW 65th Ave., Tualatin, OR
For more information and directions contact: Lance Christian at 503-238-5559 ext 1

**Yamhill County**
March 20th and May 10th, 3:00pm - 4:30pm
McMinnville Community Center
600 NE Evans Street
McMinnville, OR 97128
For more information and directions contact: Sarah Greenstein at 503.238.5559 ext 5

**Willamette Valley**
2nd Wed. of every month, 3:00pm - 4:30pm
Hilyard Community Center
2580 Hilyard St., Eugene, OR
For more information and directions contact: Gail Gallaher at 541-292-8775

**State Capitol Area**
3rd Wed. of every month, 3:00pm – 4:30pm
Salem Hospital Regional Rehabilitation Center
Second Floor Conference Room
2561 Center St. NE, Salem, OR
For more information and directions contact: Lance Christian at 503-238-5559 ext 1

**Central Oregon**
2nd Wed. of every month, 11:30am - 12:30pm
St. Charles Medical Center
2500 NE Neff Rd., Bend, OR
For more information and directions contact: Betsy Paige at 541-977-7502

**Southern Oregon**
3rd Thurs. of every month, 2:00pm - 3:30pm
Rogue Valley Medical Center Campus, Smullin Center, 2825 East Barnett Rd, Medford.
2nd Tues. of every month, 1:00pm - 2:30pm
Note: this group is for family caregivers only.
For more information and directions contact: Gail Gallaher at 541-292-8775

**Southwest Washington**
2nd Wed. of every month, 4:00pm - 5:30pm
Memorial Campus of SW Washington Med. Ctr.
Health Connection Room on 2nd Floor
100 E. 33rd Ave, Vancouver, Washington
For more information and directions contact: Lance Christian at 503-238-5559 ext 1
All people with ALS and their families from SW Washington are encouraged to attend.

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**Do you receive two or more copies of the Newsletter?**

One at home and one at work? More than one to either address? If so, please let us know. Call us at 800-681-9851 ext 6 or email info@alsa-or.org. This will help us save valuable resources in both printing and postage costs.

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Want to request a topic for a support group? Contact your local services coordinator today!