Raise awareness. Raise funds.
It’s time to Walk to Defeat ALS®.

This September, thousands of people throughout our region will lace up their walking shoes together, joining the fight against ALS. With an overall goal of raising awareness in mind – we are also working toward reaching our fundraising goal of over $600,000.

As the summer months kick into full swing, we’re looking forward to the hope, empowerment and incredible sense of community that being part of the Walk to Defeat ALS® brings each and every year. It’s easy to feel alone when living with an ALS diagnosis. Imagine being part of an event where everyone knows exactly what it’s like to walk in your shoes. Talk about a powerful experience.

A Walk Team can be two people or two hundred. That’s the great thing about the Walk; it can be whatever you want it to be. And we’re here to help you every step of the way.

The Walk to Defeat ALS® is a two to three mile, noncompetitive event. There’s no cost to participate and no required amount to fundraise. Each participant must register and remember, have fun! Custom t-shirts, banners and team themes are encouraged!

Dollars raised from the Walk to Defeat ALS® help fund local care services, as well as local and national public policy and research initiatives. Aside from being an inspirational and meaningful event, this is our chapter’s largest fundraiser of the year.

We need YOUR help to make it a success!

Registering for the Walk is easy, and if you have any questions, please contact us. Once you sign up, you will be given an online fundraising page – a place where you can upload pictures and tell your ALS story.

Remember, we are here to make the Walk to Defeat ALS® fun and easy for you and your team. We’re here to walk you through the process of spreading the word and sharing your ALS story. After all, it’s your story that connects your own community to this cause.

For more information about the Walk to Defeat ALS®, visit www.WalktoDefeatALS.org or call our office at 800.681.9851x2. Join us in September as we lace up our shoes to raise awareness, raise funds and Walk to Defeat ALS®!

Walk photos and more on page 12
Mike Spencer: Standout Volunteer

The word that best describes Mike as a volunteer is dependable. We can always count on Mike. Some volunteers have specific job preferences. Not Mike. Mike Spencer is always up for anything. He’s helped out at every different kind of event from the Dinner and Auction Gala to the tiny booth at the PDX Bike Show. He’s even helped run errands. But every time he volunteers, no matter the task, Mike is absolutely wonderful to have around. He works hard and he’s willing to do anything he can to help. Plus, he’s a real stand-up nice guy.

Mike lost his wife, Kenni, to ALS two years ago. When asked why he volunteers, he said, “I volunteer for a very simple reason. My wife Kenni died of ALS and this is my way of giving back for all the help and support that The Oregon and SW Washington Chapter offered me during my wife’s ALS journey.” Although his reason for volunteering may be simple, his impact is far from small. We are so grateful to have Mike to count on and are genuinely appreciative of everything he’s done for us here at the ALS Association. It’s thanks to volunteers like Mike that we are able to give back to families living with ALS and that’s a truly wonderful thing. Thank you, Mike, for everything you do. You really make a difference!

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.

January 22, 2013
– May 25, 2013

Michael Barkley, Susan Bates, Richard Becker, Ted Blake, Elsie Boss, Kevin Burgess, Kevan Burns, Arvin Cowger, Russell Dennick, Stephen Elstad, David Esmay, Jovita Gonzalez-Mendoza, Edward Hari, Roberta Herb, Ronald Householder, Charles Islein, Clyde Kment, Shirley Poland, Thomas Schindlbeck, David Scroggins, Jane Shuler, Sandra Soleim, Harry Staples, Russell Terry, Sandra Thomas, Phyllis Ticoulat

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

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One Goal. One Million Dollars.

We started out 2013 with a lofty goal. It was a goal to reach a milestone that our local chapter has never met before. It’s attainable, it’s reasonable, but we need all hands on deck for us to get there.

The goal – raising one million dollars. Through the Ski to Defeat ALS, the Ride to Defeat ALS and the Walk to Defeat ALS® events, personal and team fundraising will be applied to our million-dollar fundraising thermometer. Each of these events are incredibly different and offer amazing experiences, but whether participants shred, cycle, or walk, everyone works together toward this goal, and in turn, will help us further our mission to create a world without ALS.

With the record-breaking 2013 Ski to Defeat ALS behind us, and the Ride to Defeat ALS and the Walk to Defeat ALS® events just around the corner, we’re in a great position to see this goal turn into a reality. Be part of making history and sign up for the Ride or the Walk today!

For more information and to watch the progress, visit www.OneMillionforALS.org
Our Portland Staff continue to support people and their families living with ALS through meaningful home visits, clinics, support groups and community outreach. Through our regional support groups, our ALS community continues to come together to learn helpful ways to cope with the day-to-day challenges that ALS brings. Spring topics included ALS and Nutrition with Registered Dietician Kelly Bradbury from our Providence ALS Clinic, Elder Law with Nay and Friedenberg attorney Sam Friedenberg, ALS and the Family with Psychologist and Board Member Doug McClure, as well as a Transportation panel featuring Lydia Corran from Ride Connection and Leslie Adams from Performance Mobility. Thank you to all of our knowledgeable and compassionate presenters for sharing your expertise and insight with our PALS.

Also during springtime, to highlight the advocacy and awareness raising events surrounding ALS Awareness Month in May, chapter volunteer John Deeming began to visit our support groups to ensure that PALS are familiar with the National ALS Registry. John started with our Yamhill County group on April 4th, bringing fact sheets and offering to support individuals' efforts in registering if help is needed. Please visit the registry link (http://www.alsa.org/als-care/als-registry/) to get started, and don't hesitate to contact our chapter for extra support. As you will read on the website, “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. Most important, the Registry is collecting critical information about the disease that will improve care for people with ALS and help us learn what causes the disease, how it can be treated and even prevented.”

As highlighted in our Spring 2013 newsletter, expanded multidisciplinary clinics in our area continue to provide comprehensive care to people living with ALS. In addition to the ongoing efforts of the dedicated team at the Providence ALS Clinic, this spring we were thrilled to see the monthly success of the Kaiser Permanente ALS Clinic at Sunnyside as well as the first few ALS Multidisciplinary clinics at the Portland Veterans Administration Medical Center. Collaborative efforts with Ellen Kessi, ALS Social Work Care Coordinator and Tricia Strombom, ALS Nurse Care Coordinator have already proven to help streamline quality care with the dedicated support of each member of the multidisciplinary team at the VA including respiratory therapy, physical and occupational therapies, prosthetics, nutrition and speech therapy. The increased opportunity for multidisciplinary care for people living with ALS as well as the education and ALS awareness raised in the local medical communities through the processes of establishing these clinics is a positive success for our ALS community.

This spring, we offered a unique opportunity for people living with ALS to participate in a “Write Your Life Story Class.” Beginning on April 24th and running through May 31st, Judith Pulman, Literary Arts Coordinator at the Multnomah Arts Center in SW Portland, facilitated a 6-week session focused on supporting a small group of attendees in documenting the stories of their lives. By collaborating with chapter staff, the class was designed to be accessible to PALS with varying communication abilities. Attendees, including novice writers as well as more seasoned bloggers and storytellers, participated through the use of speech generating devices and adaptive computer equipment, as well as the dictation support of caregivers in the room when needed. At the end of the class, participants were proud to be able to have tangible versions of their stories to add to their blogs, compile in keepsake binders, or record on video. As each person living with ALS well knows, there are many stories to tell about your journey with this disease . . . and there are also powerful personal narratives, memories and beliefs that are not defined by ALS. All of this is part of your life story. If you are interested in attending a class like this in the future, please contact Services Coordinator Sarah Greenstein.

Our Assistive Technology Services Coordinator, Shana Tognazzini, has remained very busy this spring. In February, she attended the International Technology and Persons with Disabilities Conference in San Diego, known as CSUN. She attended several workshops and questioned many sales reps about new products hitting the market and how they would be able to benefit people living with ALS. Shana always enjoys advocating for new and innovative technology, in order to assist families back home with navigating the huge world of augmentative and alternative communication (AAC) and assistive technology. Her favorite products included a new model of the remote control speakerphone, and a joystick module that can be used to control a smartphone or tablet.

In April, Shana collaborated with a team of researchers from OHSU with their research project based on computerized speech generation and AAC. Through this connection, ten local people living with ALS were invited to participate in the project and give crucial feedback to the team, who will be wrapping up their project in June.

Shana also recently attended an ALS Association Regional Care Services Meeting in Denver, Colorado. She spoke about our chapter’s unique AAC and AT program among representatives of several other Western ALS Association chapters. During the conference, she enjoyed being able to answer questions, share
Welcome Rachelle!

We are happy to welcome Rachelle Preston as our newest staff member. Rachelle will work out of our chapter headquarters in Portland as a Services Coordinator working directly with families living with ALS, facilitating support groups and offering social work services at our affiliated clinics. Rachelle is thrilled to join The ALS Association Oregon and SW Washington Chapter and can’t wait to combine her skills and training with her passion for building relationships and being able to walk with people on their ALS journey.

While attending Portland State University and attaining her Master in Social Work degree (MSW), Rachelle interned in both day treatment and school setting where she gained experience providing counseling, facilitating support groups, and providing resources for clients and their families.

For six years, and while completing her MSW, Rachelle worked full time in the health care industry as a Resource and Referral Consultant. In this role she provided information about community and health related resources to clients throughout the US to help them navigate health and community care systems. Through this experience she provided information for those with chronic conditions and their families including durable medical equipment, support groups, Meals on Wheels, Medicaid and Medicare programs and more. Rachelle’s favorite part of this experience was learning about all of the different programs there are to help people. From grant programs to help purchase Ipads for children with autism to co-payment assistance for those with chronic pain issues, there is a lot out there!

Rachelle is a native Oregonian and received her bachelor’s degree in sociology from the University of Oregon. She proudly calls Portland home and enjoys Oregon Duck football, Zumba, concerts, travel and all the amazing sights and foods Portland has to offer. Rachelle is very close to her family and so thankful for their support. She attributes her interest in the social service field to her family’s lifelong involvement in the community.

Southern Oregon/Willamette Valley

Regional Services Coordinator Gail Gallaher has continued her support of people living with ALS and their loved ones through home visits and support groups. Outreach to local physicians and other medical providers, including home health and hospice teams, remains a priority.

Support groups in Medford have been well attended by people living with ALS, caregivers, and loyal long-term friends. Discussion topics led by our speakers include communication strategies with Julie Mondz-Kleinman, SLP; Lifeline safety with Lori Stonecipher; respiratory care with Kristi Scott, RCP; and adaptive home strategies with Ellen Downes, OT.

During ALS Awareness Month in May, Gail hosted the annual Celebration of Life gathering for friends and family of those whose lives have been touched by ALS. Also, a heart-felt letter to the editor of the Ashland Daily Tidings in May caught the attention of many readers. Barbara Roth, who has been living with ALS for over ten years, was caught in a rain storm while rolling home from the theater. A young man came out of his house and gave Barbara his umbrella so she could continue her mile-long journey home. Barbara’s thank you letter and explanation of ALS prompted calls to Gail’s office. Some wanted information and others wanted to express admiration of Barbara’s courage. Sometimes one published letter can have real impact. We salute you, Barb!

Community partners play an essential role in boosting quality of life for people living with ALS. We continue to receive generous support from volunteer Stuart Smith who builds ramps and collects donated ramp materials. Bill Weil and Grant Walker contribute their expertise in media relations. Our friends at the Medford Eagles Lodge, Betty Johnson and Rae Eatherton, support our ALS community with a monthly luncheon. They also raise funds to help pay for out-of-pocket expenses such as van tires, dental work, home medical equipment, and clothing alterations.

her practices, and network with the group of ALS Association representatives.

One of Shana's priorities continues to be working with community service providers who work with people living with ALS in our area. She provides education and training in order to help increase their awareness and knowledge of supporting the communication needs of PALS. Shana is looking forward to more opportunities for this in the coming months and encourages community services providers to contact her if interested in discussing these services in more detail.

continued on the next page
Statewide Care Services (continued from page 5)

Our hearty thanks to Stuart, Bill, Grant, Betty and Rae for always being there for us.

As we anticipate the Southern Oregon Walk to Defeat ALS set for September 8th in Medford, we welcome our own Meagan Lancaster to the support group on August 15th. Meagan will help with team registration and explain our goals for the Walk. The Walk to Defeat ALS has no bigger fans than Kristi and John Scott. Recently relocated from Portland, Kristi and John have already started building their Walk team for Southern Oregon. When Northwest Medical Respiratory & Homecare Specialists opened a new office in Medford, we gained an exceptional respiratory therapist in Kristi and two ardent supporters in the Scotts. Welcome, Kristi and John, and thanks for bringing your great energy to Southern Oregon!

Willamette Valley

Spring brought beautiful flowers to the Willamette Valley and a new Regional Care Services Coordinator, Mary Rebar. Mary worked for the Evergreen Chapter of The ALS Association in Washington State for six years, so she was able to smoothly transition into the position. In the first month, she visited ten people living with ALS and their families from Salem to Roseburg.

NuMotion of Eugene, formally United Seating and Mobility, is assisting with the Willamette Valley Loan Closet and deliveries of medical equipment. Mary has enjoyed getting to know the NuMotion staff.

The Salem Support Group members warmly welcomed Mary in March with wonderful desserts. In April, the Eugene and Salem Support Groups discussed adaptive clothing with examples of shirts and pants. Many people living with ALS shared their helpful ideas for modifying clothing. The May support groups discussed ALS Awareness Month. In June, Eric Aramori, Respiratory Therapist from Northwest Medical spoke at the Eugene Support Group. In July, the support groups topic will be how to organize friends into Care Connection groups, formerly Share the Care programs.

Please join Mary in at Papa’s Pizza, on Coburg Road in Eugene, for an evening, August 28 from 5-7 pm, to rally around the Willamette Valley Walk to Defeat ALS. Come join the fun!

In addition to all these activities across the state, Mary, Betsy and Shana traveled to Denver for the Regional Care Services Meeting with other chapters of The ALS Association. The training provided educational information and demonstrated the new respiratory equipment of the cough assist.

Central Oregon

Spring brought many opportunities to raise awareness for ALS. A big thank you to Carolyn Anderson who was able to work with the Governor to get a signed Oregon Proclamation stating that May 2013 is Amyotrophic Lateral Sclerosis Awareness Month. Carolyn was also responsible for organizing the always enjoyable Pasta-thon at the Bend Pastini Pastaria who donated 50% of the net proceeds of meals on May 13-14. Great job Carolyn, we appreciate all you do!

The May Awareness Event this year was a Celebration of Life at the High Desert Museum. This was a meaningful opportunity to again come together as a community to share stories and honor both those that we have lost to ALS as well as those that are living with ALS. The High Desert Museum offered a beautiful balance to those bittersweet memories by reminding us of the beauty of life. The High Desert Museum offers The ALS Association a group discovery pass which allows complementary admission to the museum. If you would like to take advantage of the pass for a small group of friends or family, just contact Betsy Paige 541-977-7502.

The support group in Central Oregon continues to be a wonderful opportunity to come together and connect with people living with ALS and those touched by ALS while learning about local resources in community. Recent guests include Deputy Fire Marshall, Susie Maniscalco as well as Jan Bergum from Lifeline Services that both spoke to different ways to approach emergency preparedness. Chela Sloper and Becky Dobrowski of Practically Family described their fiduciary and individual care management services. Support group meets the second Wednesday of each month at St. Charles Medical Center from 11:30 -12:30. Our quarterly caregiver support group will be meeting for the second time this year in June. Stay tuned for details!

We are grateful for our wonderful partnerships in Central Oregon including St. Charles Medical Center and The Center that allow our multi-disciplinary ALS clinic to meet every other month. The next clinic will be July 12, 2013. Norco is another one of our valued partners that graciously houses and also delivers many pieces of greatly needed durable medical equipment to people living with ALS in the community.

Betsy Paige, Regional Services Coordinator, continues to be busy visiting people in their homes, reaching out by phone and email to the ALS community, facilitating groups as well as meeting with people living with ALS at the clinic. Betsy is also active in the community participating in the Bend Senior Care Network, educating and raising ALS awareness with local churches and organizations that serve the ALS community.
Medical Equipment and Assistive Technology Loan Closets

Our Medical Equipment and Assistive Technology Loan Closets are valuable resources for people living with ALS. The closets are just one way that The ALS Association works to support people living with ALS. The Loan Closets provide a wide variety of durable equipment and technology when people need them, and are loaned to people living with ALS for absolutely no cost to the family.

If you are looking to empty your own closet and have any of the following, please contact our office and we’ll gladly put them to good use.

<table>
<thead>
<tr>
<th>Medical Equipment</th>
<th>Assistive Technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>New or barely used rehab shower chairs with wheels</td>
<td>Chattervox voice amplifiers</td>
</tr>
<tr>
<td>New or barely used manual wheelchairs</td>
<td>Switch-activated doorbells</td>
</tr>
<tr>
<td>New or barely used transport chairs</td>
<td>New or gently used “iGadgets” and Droids</td>
</tr>
<tr>
<td>Folding, portable metal ramps</td>
<td>Wireless or Bluetooth speakers</td>
</tr>
<tr>
<td>Drop arm bedside commode</td>
<td>Various styluses</td>
</tr>
<tr>
<td>Rolling rehab shower chairs</td>
<td>USB webcams</td>
</tr>
<tr>
<td>iPads</td>
<td>Switches</td>
</tr>
<tr>
<td>Rehab power wheelchairs in good condition with tilt, recliner and power leg lift</td>
<td>New or gently used headsets, microphones, Bluetooth ear pieces (must be clean and functioning)</td>
</tr>
<tr>
<td>Patient lifts</td>
<td>New or gently used mouse options</td>
</tr>
<tr>
<td>Bath seats and bath benches</td>
<td>Tech-oriented volunteers for assisting with AAC loan closet maintenance</td>
</tr>
<tr>
<td>Four wheeled walkers with seats and breaks</td>
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With Gratitude to numotion

People with ALS may need extensive durable medical equipment (DME) at some point during their illness. Our Durable Medical Equipment Loan Closet is generously hosted, free of charge, by our friends at Numotion.

Our inventory of equipment consists of over 500 items including manual and power wheelchairs, bath seats, patient lifts, and even, a beach wheelchair. Numotion stores and maintains these items at their site in Portland and with their help, the chapter provides this equipment to people with ALS up and down the I-5 corridor. This partnership with Numotion ensures our families receive free support while waiting for insurance coverage or when various DME products are not covered by their insurance plan.

Numotion is proud to partner with our chapter and is committed to our mission of empowering people with ALS and their families to live fuller lives by providing them with compassionate care and support. They truly have a passion to put lives in motion.
Are you ready for the Ride of Someone Else’s Life?
Register for the Ride to Defeat ALS today!

Tony Halford, one of our Ride to Defeat ALS committee members and a seasoned cyclist, told us two years ago when we started planning for last year’s inaugural event what it meant to have a “good” ride. He told us that to have a successful ride, we had to offer at least one of three things. First and most importantly, great route options. Secondly, he assured us that people would remember welcoming rest-stops. And finally, he stressed the importance of a great finish-line celebration.

After the 2012 Ride to Defeat ALS concluded, Tony visited our office. He told us that the Ride to Defeat ALS scored highly in all three of his categories.

“The 100 mile route was challenging but fun. The rest stops offered delicious refreshments, including strawberry shortcake, sandwiches and fresh berry turnovers. And, the finish-line celebration was so much fun”

Tony and all of the cyclists and event guests were welcomed back to the Mt. Angel Festhalle – a new community building that offers an authentic German twist that was originally built for the town’s famous Oktoberfest.

This year, participants and guests will be treated to the same amazing rest stops along the 25, 50 and 100 mile routes that showcase Oregon’s beautiful farmland. We’re excited to introduce a shorter Family Fun Ride, which will wind through Mt. Angel and is a great option for both kids and parents.

Upon returning to the Finish Line Celebration, dinner from Silverton’s own Wooden Nickel Catering will be waiting for you, as will beer from the local Seven Brides Brewing and wine from Cupcake Vineyards.

Ken Feldhaus and his team Ken’s Kismet is back again and already working to hold on to their 2012 traveling trophy for earning the awards for top fundraising participant and top fundraising team.

The cost is just $35 to register and each participant (ages 11 and up) are required to raise at least $150 to support The ALS Association. The goal is to raise $100,000 to support local care services, national public policy efforts and international research initiatives.

We have a lot of surprises in store for you this year at the Ride to Defeat ALS, presented by Alpenrose Dairy. For more information or to register, visit www.OregonRidetoDefeatALS.org or call 800.681.9851x2.
2013 Ski to Defeat ALS Breaks Records

A storm hit the slopes of Mt. Hood Meadows on Saturday, April 13th and we're not just talking about the wind and the snow that pummeled the mountain. There was another kind of storm, and it was all about defeating ALS!

With a goal of raising $150,000, 250 participants rallied their communities, shared their stories about ALS and together, raised over $170,000 – dollars that will directly impact our local chapter and the people living with ALS in our region. Thanks to a great partnership with Mt. Hood Meadows, participants and guests enjoyed an incredible event.

Congrats to honorary chair, Fred Noble, for earning the traveling trophy for being the top fundraiser and leading the top fundraising team.

Karen Woodruff took home the trophy for racking up the most vertical feet skied in the women's category, and Craig Pieringer took home the trophy for accumulating the most vertical feet in the Men's category. Team Fredinator collected the most vertical feet in the team category.

Once again, perhaps one of the most memorable moments came from The ALS Association's partnership with Oregon Adaptive Sports. Through this partnership, more than twelve people living with ALS snapped up the chance to head down the mountain in adaptive equipment. Some were first-time skiers, and some had been veterans of the snow sport.

Kudos to the top fundraising teams:
1. Team Fredinator - $54,105.42
2. Cerus Industrial - $12,820
3. Deb's Downhill Racers - $7,491.50
4. T.E.A.M. Mike Lopez - $6,963.50
5. Team Kyte - $6,838

And the top fundraisers:
1. Fred Noble - $28,376.03
2. John Peterson - $5,000
3. Chris Cate - $2,770
4. Carl Tuma - $2,486
5. Kevin Wright - $1,930

Save the date for Saturday, April 12, 2014 as we’ll hit the slopes of Mt. Hood Meadows for the 2014 Ski to Defeat ALS. For more information, email ski@alsa-or.org. The 2014 event website will open November 1st, so keep your eyes and ears open to ensure you are one of the first to sign up for this incredible and inspirational day.
Hillsboro High School rallies around the Walk to Defeat ALS®

This past spring, Madisyn Miller rallied her high school to support her Walk to Defeat ALS® team.

“Getting the news about my dad having ALS has been one of the greatest impacts as well as the worst. I was inspired as student body president to create an event at Hillsboro High School in which royalty courts would raise money for The ALS Association. After two weeks of competitive fundraising, we ended up raising $2,000 worth of making a difference in the lives of all people living with ALS. I am very proud of my high school and the impact we’ve made.”

Thanks to Madisyn, pictured here with her dad, Darryl Crawford, and Meagan Lancaster, fundraising manager at The ALS Association.

JOIN US IN 2013!
Volunteer Opportunities

With two successful events under our belt already this year, we’re starting to get really excited for what’s to come. But, none of these events are possible without the help of our amazing volunteers! Find below a list of events where you can get involved:

2013 Oregon Ride to Defeat ALS presented by Alpenrose Dairy
We’re still looking for approximately 15 volunteers to help out at the upcoming Ride to Defeat ALS on Saturday, July 13th, at the Mt. Angel Festhalle in Mt. Angel, Oregon.

*We’re particularly looking for volunteers who would be interested in helping out with kids activities! Please let us know if this sounds fun to you.

Walk to Defeat ALS®
Can you believe it’s almost Walk season?! We’re recruiting volunteers at all six of our walk events.

Bend – Saturday, September 7th
Medford – Sunday, September 8th
Salem – Saturday, September 14th
Eugene – Sunday, September 15th
Vancouver – Saturday, September 21st
Portland – Sunday, September 29th

For more information contact Anna Holmes, Events & Volunteer Coordinator, at annaholmes@alsa-or.org, or reach her by phone at (503) 238-5559 x 7. We would love to have your help!

The 2013 ALS Dinner & Auction Gala charts new territory for ALS.

The evening of Saturday, March 9, 2013, welcomed more than 600 guests, patrons and volunteered gathered at The Oregon Convention Center for the 2013 ALS Dinner & Auction Gala. It was an incredible night of inspiration, love and a shared vision to chart new territory for ALS by bringing in crucial funding for care services and research initiatives. Guests were treated to a delicious dinner, silent auction, live auction and a variety of surprises through the evening. The chapter raised more than $300,000; ensuring local services will remain and even expand for people living with ALS in Oregon and SW Washington and their families.

The live portion of the evening was kicked off by a warm welcome from emcee Tracy Barry of KGW. Auctioneer Graham Crow engaged guests on every level, offering exciting opportunities to participate for everyone.

One of the many highlights of the evening was the keynote speaker, Bo Stern. Stern is an author, teacher, and most significantly, a wife and caregiver to her husband Steve, who is living with ALS in Central Oregon.

Stern’s appeal, as so many recounted, spoke the words we so often wish we articulate. She spoke of the battle of living ALS, their personal journey, and the choice to not let ALS take the life left in her husband’s days. She spoke of the beautiful battlefield that is ALS and as she did so, she left her mark on every heart in the room.


The 2013 ALS Dinner & Auction Gala was underwritten and supported by:
Raising Awareness of ALS!

The month of May was officially ALS Awareness Month. Our chapter seeded the media with stories for both television and print. We were happy to have news pieces about ALS published and broadcast across all of Oregon and SW Washington. We were proud that the City of Vancouver and Governor John Kitzhaber, on behalf of the entire state of Oregon declared May as ALS Awareness Month.

This year we launched an online campaign for people to share their ALS stories. In case you missed them online, here is a select group of the many inspiring stories that were shared from across the chapter. We hope you find them as meaningful as we did.

A Caregiver’s Voice by Andrea Bullock, Newport, OR

This is my story, the story of a wife, a mother and a caregiver. Cory and I were always good “little squirrels” working hard and saving our nuts for the future. So when we were faced with the devastating diagnosis of ALS in 2009, we had to quickly learn how to be grasshoppers and live in the moment. At first, I thought Cory was crazy when he threw the idea out there to travel across the country, with our then 5 year old daughter Emma, in a recreational vehicle. With time not on our side, I knew he was right (but don’t tell him I said that). We needed to find a way to make a lifetime of memories for our daughter quickly. So, two years ago, we set out on “The Adventure of a Lifetime” (said in a deep, loud voice with a slight echo). We rented out our house, put what was important in storage, bought an RV and headed West.

From Texas to Montana, California to Massachusetts, our travels were an unimaginable adventure. We hiked the most amazing parks in Utah, California and Wyoming, white-water rafted down the Rogue River in Oregon, and visited our nation’s most cherished National Parks and monuments. We even hit Disney World and caught a glimpse of the Cherry Blossoms in spring at our Nation’s Capitol. The time we spent traveling and creating memories was an opportunity of a lifetime that I am truly grateful for. Emma and I will cherish these experiences for the rest of our lives.

All of this sounds quite lovely, but don’t get me wrong, there are bad days - really bad days. ALS sucks! Every day, I make the choice to smile, laugh my way through it all, and live in the moment. This isn’t always easy, but it is so much healthier than the alternative (at least that is what I tell myself). Sometimes I laugh to think what I would look like if Cory had to do my hair and make-up every day, although learning to shave him was not exactly easy. Caregiver is so much more than a word; it is who I am, and I am so honored to be this person for my Love. It is hard to watch the man you planned to spend the rest of your life with, the father of your beautiful daughter, the man that held you and made you feel safe struggle with simple, everyday tasks and just waste away right before your eyes.

This is the reality of the disease. ALS may rob me of my husband and steal my daughter’s father, but in a strange way I feel as though I have gained so much. A connection to life that many may never grasp and a feeling of love and compassion so deep I am often overwhelmed by it. I am truly inspired by the love, strength and courage I see in so many facing this disease. I share our journey with the hope to inspire everyone to live in the moment, like today is a gift.

While Andrea, Cory and their precocious daughter Emma hail from the great state of Texas, they now make their home on the Oregon Coast just outside Newport, OR.

Living with ALS - My Voice by Nicolasa Mohs, Salem, OR

My life changed in October of 2011 when I was diagnosed with Amyotrophic Lateral Sclerosis, also known as Lou Gehrig’s disease. In a span of less than two years, this disease has robbed me of my independence, including my ability to drive or speak for myself with authority. I have gone from regularly attending exercise classes and weight lifting and running to depending on my husband for helping me with my most basic needs like showering, dressing, cooking, driving the grandchildren around and going to their games. I now rely on using a walker at home and wheelchair when we venture out,
as my leg strength has diminished. My speech is slowly failing as ALS deteriorates my throat muscles.

I live one day at a time, and each day I thank God I am still alive and that I still have minimal ability to talk, eat, and even breathe with minimal medical support. My dreams are to live a long life like Stephen Hawking and to see a cure for ALS in my lifetime, to teach my grandson to be the best reader, to watch my daughter Erika’s graduation from medical school and to attend my daughter Crystal’s graduation from law school. My immediate goals are to teach my daughters to cook their favorite dishes, to love and spoil my grandchildren, and to be the best ambassador for Jesus Christ as I suffer with this affliction.

No matter what this disease takes from me, it can never take the love of my family and the support of my good friends. My church family is very much appreciated for their visits, their prayers, the meals and their unending support, and for that, I will always be grateful.

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**A Survivor’s Voice by Jeanean Rauch, Corvallis, OR**

My husband died four years ago from ALS, and it is fitting this year he would have been 39 years old. I wish he were here to start his last year in his 30’s. I also wish he were here to celebrate his son’s 7 year old birthday in three weeks. Our ALS journey started when he was rock climbing. He noticed his big toe was not moving as well as the others. We shrugged it off as nerve damage from his whitewater kayaking days and shoving his feet into small boats and rock climbing shoes. After some time, more symptoms, and many doctors later, we were told what we already suspected. I remember lying in bed in the middle of the night nursing my five month old son and realizing that Kevin was going to die.

My world had changed, and we had to face it. We did face it, even though at times it was kicking and screaming. We wanted this nightmare to end. Kevin’s course of disease was typical of many ALS patients, and he was fortunate enough to try different treatments. He participated in a clinical trial knowing that it may prolong his life minimally but more importantly would provide data for future ALS patients.

Kevin was determined, persistent and bright, and he carried that into his life with ALS. He helped develop a climbing crag near Portland, and when he could no longer climb, let alone walk, his friends carried him down a steep trail so he could spend the day with them as they climbed. He was loved and respected by so many people and even as he suffered the long and torturous progression of becoming paralyzed, he remained a leader and beacon for others. He became our teacher, and we carry the lessons of life and death with us now.

The ALS Association was there for us when we were in need. Whether it was equipment, navigating finances and insurance processing, or providing emotional support and education about disease progression, they were available. Just knowing they were there provided a level of comfort that we otherwise would not have had. I have so much gratitude for the people who stepped forward to help us and who gave us gifts both physically and emotionally during that time. What does it mean to have ALS a part of your life? It means I no longer have my husband here, and my son no longer has his father. But it also means that we have experienced a deeper connection to life and others and truly know what infinite love is. I hope for a cure. I hope for awareness. I hope for action. I hope for treatments.

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**A Child’s Voice by Samantha Candilora, Vancouver WA**

My name is Samantha. My dad, Toby, had ALS. He was diagnosed in 2008 and died 2009. I would love to see the world without ALS because I don’t want any other kids dealing with what my sister and I did. Why I still do the ALS walks and still help the ALS Association is because I want to be there when it is announce they found a cure for this disease.
Combining Growth Factors May Benefit ALS Treatments

When it comes to amyotrophic lateral sclerosis (ALS), two growth factors may be better than one. That’s the conclusion from a new study from research supported by the Wisconsin Chapter of The ALS Association and led by scientists at the University of Wisconsin at Madison.

Growth factors are proteins produced by one set of cells in the body that help promote the health of other cells. Previous work has shown that both VEGF (vascular endothelial-derived growth factor) and GDNF (glial-derived neurotrophic factor) can promote the survival of motor neurons in models of ALS. Motor neurons are the cells that die in ALS, leading to paralysis.

To test whether the two growth factors together could provide more benefit than either alone, Masatoshi Suzuki, Ph.D., and colleagues engineered stem cells to produce both growth factors and then injected these cells into the muscles in a rat model of ALS. The combined treatment increased lifespan and improved features of the motor neurons at the point where they contact muscle. The study was published in the journal Molecular Therapy.

“This study provides support for the idea that delivering growth factors to muscle may be beneficial in ALS,” said Lucie Bruijn, Ph.D., Chief Scientist for The ALS Association. “Further work will be needed to explore this option, but it has the advantage of being less invasive than delivering the same growth factors to the spinal cord.”

Claire Peterson and her late husband, Rod, lost their son, Ernie, to ALS. To keep Ernie’s dream of a cure alive they established a gift through their estate plan in his memory. “I challenge anyone affected by ALS to research the various gift options The ALS Association offers,” Claire urges. “Down the line, there will be a cure and you will want to know that you were a part of it.”

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.

The Legacy Society
Your Gift, Your Way
Claire Peterson
Successful Writer for Television
Wife and Mother
Philanthropist

Are you seeing information on alternative therapies to treat ALS? For a scientific review of these alternatives, visit www.ALSUntangled.com

Be sure to check out and visit our website often
www.alsa-or.org

It is constantly being updated with information on events as well as current care services.
Making a Difference in Washington DC

This last May, hundreds of families living with ALS stormed Capitol Hill to advocate for ALS research with the goal to bring new treatments for ALS from the lab bench to the clinic sooner than later. On May 8-11, 2013 these families attended the National ALS Advocacy Day and Public Policy Conference. Our Oregon and SW Washington delegation included Executive Director Lance Christian and the families of people living with ALS, Brian Epp of Battleground, Washington, Ken Feldhaus of Hillsboro, Oregon, as well as Courtney Kyte of Portland, Oregon who represented her father who is living with ALS in Oregon.

As part of the conference, they spent the day on Capitol Hill meeting with the Southwest Washington and Oregon congressional delegation. There was a face-to-face meetings with Senator Jeff Merkley, as well as meetings with Representatives Peter DeFazio, Suzanne Bonamici, and Southwest Washington Representative Jamie Herrera Beutler. In other offices, we met with key healthcare staff.

Developing a treatment for ALS it is a long process, which begins on the lab bench with basic research and, fifteen or more years later, ends with FDA approval. It is an expensive process, which can cost more than a billion dollars. The public policy priorities advocated for in Washington were strategically chosen because each priority - continued funding of the National ALS Registry and continued funding of the ALS Research Program in the Congressionally Directed Research Program at the Department of Defense - helps to overcome the challenges of treatment development. Ultimately, they may help us find the cause, treatment and cure for ALS.

Congratulations and thanks to Brian, Ken, Courtney and their families for representing all people with ALS across Oregon and SW Washington. This trip was generously supported by your donations as well as sponsorship from Alpenrose Dairy. We are grateful for the support.

To become stay up to date on public policy happenings and to become an advocate for The ALS Association, visit www.alsa-or.org.
### Support Group Schedule

**Portland Metro Area**  
1st Wed. 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.

### State Capitol Area**  
3rd Wed. of every month, 3:00pm – 4:30pm  
Salem Hospital Regional Rehabilitation Center Fourth 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.

### 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

### 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.