Be one in a million.
We’ve almost raised $1 million!
We can do it with your help . . .

In 2013, we set an aggressive goal to raise ONE MILLION DOLLARS between the Ski to Defeat ALS, Ride to Defeat ALS and Walk to Defeat ALS® events.

We’re so close. Actually, we’re really close. But we need your help to get there!

There is still time left for us to reach the million dollar mark, for the first time in our chapter's history!

The Walk to Defeat ALS® website closes on December 31st. So between now and then, we encourage all of our supporters to do their part:

1. Donate to a registered walker in your area.
2. Fulfill your fundraising goal by reaching out to friends and family one more time to ask for support.
3. Ask your company to match your gift.

Visit www.WalktoDefeatALS.org today and search for our Walks in Oregon and SW Washington. You can also call 800.681.9851 ext 3 or email us at walk@alsa-or.org.

Let’s do this… together!
More funding only means more care services and more research results!

Follow our progress at www.OneMillionforALS.org

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CHANGE OF ADDRESS:
If you’ve recently moved, give us a call or send us an email and let us know your new address. If you no longer want to receive this newsletter or other Chapter information, please help us save on costs and let us know. Thank you!
Good Luck Meagan! We’ll Miss You!

It is with mixed emotions that we announce the departure of Meagan Lancaster from our organization. Meagan started with us in July of 2008 and has been instrumental in the growth of our chapter with her hands on support of our fundraising and awareness efforts. As many of you have experienced, Meagan brings a positive attitude and a smile to everything she does. She has gone above and beyond in her efforts to ensure our ALS community is heard and well supported.

On October 21st, Meagan started work for JDRF (Juvenile Diabetes Research Foundation) as their Regional Manager. In her new role, she is supporting their chapters across the Western United States in their fundraising endeavors. We are thrilled that she has found an opportunity that she will enjoy and will take her to the next professional level. We are sad that she will not be with us every day. But, this is not goodbye as Meagan will share her passion for defeating ALS by volunteering and attending our events when she can. ALS will always be near and dear to her heart.

We will be filling this position shortly, but in the meantime, you can direct any questions, comments, requests, etc… to Aubrey McCauley, Development Director at AubreyMcCauley@alsa-or.org or 503.238.5559 ext 3.

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.


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

Rebecca Pace comes to us from the Greater Philadelphia Chapter of The ALS Association, where she spent over three years as their Events and Volunteer Coordinator. In this position, Rebecca coordinated the Walk to Defeat ALS® and other Chapter events, helped Community Partner event organizers lead successful fundraisers, and managed the Young Friends of The ALS Association. She was passionate about coordinating the volunteer program and is thrilled to continue this work in Oregon and SW Washington. Graduating from the University of Pittsburgh with a degree in Communication, Rebecca is an east coaster born and raised. However, Portland and the west coast are quickly stealing her heart! She enjoyed an exciting and successful first Walk Season and looks forward to meeting and working with our ALS community to further our mission.

You can contact her at RebeccaPace@alsa-or.org or 503.238.5559 ext 7.

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:

- Richard Becker, Karen Brusse
- Tomi Carlston, Hazel Childs
- Wayne Clements, Barbara Collins
- Elizabeth Dial Mills, Patricia Dunaway
- Gary Hatcher, Marilyn Haugh
- Elizabeth Kitzmiller
- Robert Kuechmann
- Fred Noble, Dennis Payne
- Linda Peckham, Mary Jo Picascia
- Jo Anne Risley, David Service
- Jean Whisman

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 Oregon and SW Washington Chapter 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 ext 6 with corrections so our records can be changed and updated.
NW Oregon & SW Washington

In the Portland Metro area, services staff Lance Christian, Sarah Greenstein and Rachelle Preston continue to serve individuals living with ALS and their families through multidisciplinary clinic representation at Providence, Kaiser Permanente and the Veteran’s Administration. They engage in numerous home visits to provide initial support to newly diagnosed families as well as ongoing care to families throughout the progression of the disease, including bereavement support upon the loss of a loved one.

The summer months and first few weeks of autumn brought opportunities for members of our ALS community to come together to share information, experiences, and support in our ALS Support Groups with topics ranging from Feeding Tubes & ALS with Dr. Mike Phillips to Hospice Services with the Providence Hospice Nursing team in Portland. We learned about Assistive Technology 101 with our own Shana Tognazzini and The ALS Registry with dedicated volunteer John Deeming in Vancouver. We were also honored to have Dr. Lou Libby join our July Family Caregiver’s support group to engage our family caregivers in a frank, open, and sensitive conversation about respiratory concerns in advanced stages of ALS.

Thank you to our presenters for enriching the informational value of our support groups, and thank you to our attendees for creating connections, as well as supporting one another through words and actions in support group and beyond.

As the rain pounded the pavement at our Vancouver and Portland Walks to Defeat ALS in late September, the power of community was tangible as people living with ALS and their caregivers rallied teams of support to come together in the thousands to ensure that nobody in our community is alone on their path with ALS. It is with this momentum that we look to the coming months with gratitude for an opportunity to honor the caregivers in our community.

Assistive Technology Coordinator Shana Tognazzini has been very busy over the summer completing a record number of evaluations for people with ALS to get insurance funded speech generating devices. This of course has led to many busy days setting up and helping people learn to use their devices. Helping people stay functional with their communication and computer access has kept Shana’s services in high demand.

Southern Oregon

The Southern Oregon Walk to Defeat ALS® in Medford was an uplifting and successful event. With several hundred in attendance and new Walk Teams joining the ranks of loyal long-standing teams, we enjoyed a beautiful day free of forest fire smoke! We thank our new master of ceremonies, Leslie Haze for rallying our troops and bringing her personal enthusiasm to Walk day. And tremendous thanks to every person who came out, who walked and rolled, and raised awareness and needed funds!

Services Coordinator Gail Gallaher continues to serve the ALS community through home visits, support groups, and the delivery of services. Our loan closet partnership with NuMotion has strengthened since their recent merger, and Laurie Sanderson, Medford operations manager has gone the extra mile moving home medical equipment wherever it is needed in our region. Our Respite Fund for family caregivers is much appreciated by several families, and the new In Home Care Program is now successfully underway via our partnership with Right At Home Care Services.

In the months leading up to the Walk, media and marketing guidance; Stuart Smith and Betty Lou Lore for assistance with building ramps and storing building materials; Jeff and Taylor Holverson and the Shields family for Walk day heroics; Tami Bowden for volunteering at Walk registration would be without volunteers? Thanks to Bill Weil for media and marketing guidance; Stuart Smith and Betty Lou Lore for assistance with building ramps and storing building materials; Jeff and Taylor Holverson and the Shields family for Walk day heroics; Tami Bowden for volunteering at Walk registration
Regional Care Services

Thank you to our 2013 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, Wells Fargo and Numotion.

REGIONWIDE CARE SERVICES

continued on the next page

every single year; Betty Johnson and Rae Eatherton for hosting luncheons and raising funds through the Medford Eagles Lodge. ALS Family Caregivers will be honored at a luncheon November 12th at Applebee’s in Medford. We welcome former family caregivers as well as those currently providing care. We salute the commitment, generosity and compassion of all who serve their loved ones living with ALS.

Willamette Valley

Willamette Valley Services Coordinator Mary Rebar has had an active schedule that includes outreach and home visits to PALS in the Roseburg area and the coastal areas of Lane and Douglas Counties, as well as lots of visits in Salem and Eugene. Working with our partners at NuMotion, Mary has been active loaning medical equipment to families that range from bathroom equipment to power wheelchairs, and everything in between.

The Salem and Eugene support groups offer congenial support. One member in Salem generously bakes cookies every month for all to enjoy. And the Eugene group had a lively discussion when a fellow PALS from the Midwest came to visit. John Deeming, volunteer extraordinaire, attended both the support groups to encourage participation in the National ALS registry. If you are living with ALS or a family member of someone living with ALS, join us at support group. You will be warmly welcomed.

Central Oregon

Central Oregon is so fortunate to continue to offer ALS Clinics every other month at The Center. We appreciate the talented clinicians that are able to offer their time and expertise to offer coordinated care to PALS in the community. We appreciate the continued support of Dr. Vivian Ugalde (Physiatrist), Dr. Chris Kelley (Pulmonologist) and Dr. Dick Maunder (Palliative Care Physician) for offering their time and expertise at this valuable Clinic.

The monthly support group continues to be very dynamic and well attended. Invited speakers over the last couple of months include Norco’s lead respiratory therapist Stacy Grasty who was able to provide an overview of important respiratory equipment and insurance requirements. Stacy is committed to our PALS in the community and often makes home visits for ongoing education and assessment.

We were also pleased to welcome Dr. Dick Maunder and social worker Kim Dent from the palliative care program, Advanced Illness Management at St. Charles Medical Center. In addition to joining the ALS Clinic Team, Dr. Maunder also has the ability to do Outpatient home visits with PALS to address concerns related to discomfort, quality of life, and advance directives. A final highlight from a recent support group was when Glenn Asbury shared his “Top 10 Bits and Pieces of Living with ALS”. Glenn, thank you for sharing your wisdom, your expertise and your humor with the group!

In September, we had our quarterly caregiver luncheon at FlatBread Community Oven. This luncheon is a unique opportunity for current and past caregivers and family to come together informally and connect. This ever evolving group continues to be a very caring and supportive group of people. Our next luncheon will be in November when National Caregiver Month is celebrated. Stay tuned for more details.

In addition to participating in the ALS Clinic and facilitating the monthly ALS Support Group, Betsy Paige, Regional Services Coordinator, keeps very busy doing home visits and community outreach to ensure optimal communication and partnership with home care agencies, hospice and community resources.

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, formerly known as United Seating & Mobility and ATG Rehab.

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.
You are in Charge of Your Medicare Benefits

Medicare’s Fall Open Enrollment period occurs each year from October 15th to December 7th. During this time, people with Medicare can make changes to their existing Medicare coverage. Changes you make during this time will take effect on January 1, 2014. To avoid enrollment problems, it’s best to call 800-MEDICARE when making any changes to your Medicare health and/or drug coverage.

During Fall Open Enrollment, people with Medicare can make the following changes:

- Switch from Original Medicare to a Medicare Advantage Plan
- Switch from one Medicare Advantage plan to another Medicare Advantage plan
- Join a Medicare Prescription Drug (Part D plan) for the first time
- Switch from one Medicare prescription drug plan to another Medicare prescription drug plan.

Keep in mind that your Medicare benefits may change from year to year. Before making changes to your Medicare coverage during Fall Open Enrollment, you should review your current health and drug coverage to see whether your benefits and costs will change in 2014.

If you get your Medicare benefits through Original the traditional Medicare program run directly by the federal government, you should take a look at the 2014 Medicare & You handbook. In mid to late September, this handbook is mailed to everyone who has Medicare and includes a summary of Original Medicare benefits and costs in 2014. If you have not received the Medicare & You handbook, you can download the handbook online at www.medicare.gov or call 800-MEDICARE and ask that a copy be mailed to you.

If you have a Medicare Advantage Plan or a Part D Plan, you should receive a notice in the mail called an Annual Notice of Change or Evidence of Coverage. Plans are required to send these notices to plan members by September 30 of each year. Take a look at these notices to see if there will be any changes made to your Medicare coverage in 2014. Remember, it’s best to make sure that the health care services you need, the healthcare providers you want to use, and the drugs you take will be covered by your plan in the upcoming year.

If there aren’t any changes and you’re satisfied with your Medicare coverage, you don’t need to make any changes during this time. However, if there will be changes to your health and drug coverage in 2014, or if you’re unsatisfied with your current coverage, you have the right to make changes during Fall Open Enrollment.

Chapter Launches a new regionwide In-Home Care Program

Over time people living with ALS need help with performing activities of daily living such as bathing, dressing, eating, and assistance with personal hygiene. Usually, this work is performed by immediate family members usually the spouse. As paralysis increases, the care giving need and workload for family caregivers increases and the ability of the family to meet the myriad of care giving needs can become taxed. In addition caregivers who work 24/7 face immense risks of burnout and stress.

This September, the ALS Association Oregon and SW Washington Chapter, with community partner caregiving agencies, started a new In-Home Care Program to address this need. Through this program, we provide and financially cover in home caregiving services for a limited number of people with Amyotrophic Lateral Sclerosis. This includes up to six hours of caregiving help in the home per week.

This program serves those who qualify for no other in-home assistance programs and need help with personal care. Applications poured in from all service areas and care is provided on a first come first served basis.

Currently we are working on contracts with local care agencies and have been scheduling intake appointments. Families get to determine what are the most important needs and how they coordinate their schedule to make it most helpful. We hope that this program improves quality of life for both the caregivers and the person with ALS.

We continue to accept applications for our waiting list. If you are interested in applying or have questions please contact Services Coordinator, Rachelle Preston at homecare@alsa-or.org or 503.238.5559 ext 5.

Affordable Care Act and People with ALS.

**Question: I have ALS. Do I need to enroll in the health care exchange for the Affordable Care Act?**

**Answer:** If you have Medicare, Medicaid, Employer provided health insurance, or Veteran’s Administration health care benefits, you do not need to do anything related to the Affordable Care Act. Your plan, benefits and coverage is not affected by The Affordable Care Act. If you are uninsured, or purchase a private insurance policy, you may want to visit the Oregon or Washington healthcare exchanges to see if there is a plan that provides better coverage and/or is more affordable.
Emergency Preparedness for People with ALS

By Alisa Brownlee, ATP and Sara Feldman, DPT

Emergencies and disasters can strike quickly and without warning, forcing people to leave or be confined in their home. For the thousands of Americans with ALS, emergencies such as fires, floods and acts of terrorism present a real challenge. It is important that people with ALS and their family members make plans to protect themselves in the event of disasters. This needs to be addressed not only at home, but also when away from home, such as at work or on vacation.

In addition, first responders need to know how to work with people with ALS to evacuate them safely and quickly. Emergency planners must ensure that shelters are accessible to people with a variety of disabilities.

The first step is to prepare. It takes work but it is worth it! The more you do, the more confident you will be that you can protect yourself.

The second step is to make a plan, which should include these items:
- Know what kinds of disasters could happen in your area and consider what your environment might look like after one occurs.
- Complete a personal assessment and personal support network of family, friends, relatives, neighbors, roommates and co-workers who could assist you at a moment’s notice.
- Make an emergency information list so others will know who to contact if they find you unconscious, unable to speak or if they need to help you evacuate quickly.
- Compile a medical information list that contains the names and numbers of your doctors, your medications, dosage instructions, and any existing conditions. Make note of your adaptive equipment, allergies, and any communication difficulties you may have.
- Keep at least a seven-day supply of medications on hand. Ask your doctor or pharmacist what you should do if you cannot immediately get more.
- Identify evacuation routes and safe places to go during a disaster.
- Keep a disaster supply kit in your home, car, workplace or anywhere you may spend time, including such items as food, water, a first aid kit, adaptive equipment, and batteries.
- Show others how to operate your wheelchair or other assistive devices.
- Work with local transportation and disability services (e.g., Paratransit, Independent Living Centers) to plan ahead for accessible transportation if you may need that for evacuation or other reasons during a disaster.
- Keep in mind that during an emergency, you may need to explain to first responders and emergency officials that you need to evacuate and shelter with your family, service animal, caregiver, or personal assistance provider so they can provide the support you need to maintain your health, safety and independence.

The third step is to be informed. There are various web sites for preparedness:

Emergency Preparedness Guidelines for People Living with ALS and their Families
http://www.diversitypreparedness.org/Topic/Subtopic/Record-Detail/18/resourceid--20154/

November is National Caregivers Month!

The ALS Association Oregon and SW Washington Chapter joins with other chapters nationwide in taking time out to express appreciation to family caregivers as well as bring resources to their attention. There will be specific links on our website during the month of November focusing on caregiving tips and resources, our respite care fund, and taking extra time out to thank the caregivers in our community. In addition to these resources as well as our monthly Family Caregiver Support Groups, we are pleased to be offering the following:

NW Oregon and SW Washington: A 6 week workshop for caregivers entitled Powerful Tools for Caregivers, from October 7th – November 11th. With a group of 10 caregivers signed up, it promises to be a meaningful resource. We would like to invite all family caregivers to an afternoon in their honor on Thursday afternoon, November 21st from 4:00-5:30pm at Legacy Meridian Park in the Health Education Building. We will celebrate, thank and honor caregivers with light refreshments and special tokens of acknowledgement including chair massages for all. Whether you are a regular Family Caregivers Support Group attendee or have never attended a support group, you are invited to join us!

Central Oregon: Quarterly Caregivers Luncheon. Contact Betsy at BetsyPaige@alsa-or.org for more details.

Willamette Valley: Contact Mary at MaryRebar@alsa-or.org for more details.

Southern Oregon: ALS Family Caregivers will be honored at a luncheon November 12th at Applebee’s in Medford. We welcome former family caregivers as well as those currently providing care. We salute the commitment, generosity and compassion of all who serve their loved ones living with ALS.
The 2013 Oregon Ride to Defeat ALS presented by Alpenrose Dairy brought together over 400 riders, volunteers, guests and sponsors to further our mission of creating a world without ALS.

The day did not disappoint. Cyclists were greeted by a sunny morning on moderately challenging but beautiful routes of 25, 50 and 100 miles through the scenic landscapes surrounding Mt. Angel. Our newest route option, the Family Fun Ride, took our youngest supporters on a 3-mile loop through the town of Mt. Angel with fun activities throughout and ending with a Glockenspiel song and dance – as well as tasty ice cream provided by Alpenrose Dairy.

Our finish-line celebration was the perfect ending to an exciting day, with performances by The Pop Rocks and the Jim and Alan Show, a bounce house and fun kids’ activities, delicious food compliments of The Wooden Nickel, and beverages from Cupcake Wines and Seven Brides Brewing.

Your participation helped create much needed awareness and over $118,000 in funding for our mission.

Congrats to the following achievements!

**Top 5 Teams**
1. Ken’s Kismet $11,865
2. Ran’s Fans $7,127
3. Team 100 sMiles $6,748
4. Flying Mavericks $6,079.50
5. Guys & Gals Riding for PALS $5,385

**Top 5 Fundraisers**
1. Ken Feldhaus $7,490
2. Susan Cassidy $4,504.50
3. Barry Childs $3,150
4. Glenn Montgomery $3,075
5. Mike Spencer $2,450

Interested in participating in 2014? Let us know at: www.OregonRidetoDefeatALS.org. And be sure to Save the Date for July 12, 2014 at the Mt. Angel Festhalle as we continue to ride to defeat ALS! Contact Rebecca Pace at ride@alsa-or.org to learn more.
Hit the Slopes with Us in 2014!

The Ski to Defeat ALS, now in its third year, promises to be an event not to be missed.

Ski and snowboard season is upon us, and we’re ready for another epic Ski to Defeat ALS at Mt. Hood Meadows. With a lofty goal of raising more than $150,000, hundreds of skiers and snowboarders will hit the slopes with one goal in mind – defeating ALS.

Whether you’re an avid skier or just dust off your boots once or twice a year, this event is for you! With fundraising challenges, vertical feet challenges, and an overall great time, save the date for April 14th and join us as we Ski to Defeat ALS!

Here’s all you need to know:

• Registration will open in December. If you are interested, you can let us know today by calling 800.681.9851x3 or emailing us at ski@alsa-or.org. We will make sure you are one of the first to sign up!
• The cost is $75 to register and each participant must raise at least $150. Don’t worry – the fundraising is the easy part! We do have a NEW special registration fee of only $25 for current 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 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 have separate categories for men, women, and an overall team trophy.
• You can form a team and then invite your friends and family to join you!
• We’re here to help – just call us or email us at ski@alsa-or.org if we can sign you up, answer any questions, or help brainstorm ways to engage your community.

Thank you Megan Miller!

Raising funds and awareness to serve our ALS community truly takes a village. At the center of this village are our treasured volunteers, without whom we could not put on the events and programs that help further our mission. Every volunteer has a story, a reason why he or she donates countless hours to the cause. Each story is unique, but many have the same thing in common – paying tribute to a loved one who lives with the terrible disease that is ALS.

One of our favorite stories comes from Megan Miller, an upbeat, hard-working, and reliable volunteer. She attends every event she can, and helps rally the rest of the village in setting up, acting as our registration guru, and filling in wherever needed. It is amazing hearing why she does what she does for us, and for her loved one – her Uncle Steve Stern who is living with Lou Gehrig’s Disease.

“My uncle, Steve Stern, is one of the greatest men I know. He is kind, strong, and wise. Our world was rocked the day we found out he was diagnosed with ALS at the young age of 48. Since then, our already tight-knit family has rallied together and raged war against the monster that is ALS. It is a degenerative, devastating disease and the uphill battle has been a hard one. With such a grim diagnosis, it was easy to feel lost in a sea of hopelessness and helplessness.

Luckily I was blessed to be introduced to the remarkable staff at the ALS Association of Oregon and Southwest Washington. I volunteer because it is a step forward. By joining forces with The ALS Association at Walks, Ski Events, the Ride, and the Gala we have raised awareness about the disease, exceeded fundraising goals, and encouraged each other in this ongoing battle. Seeing the strength and courage of the patients is encouraging and simply inspiring. The Association has empowered me to join in the fight in a tangible way and I count it a blessing to fight alongside them.

Battles are won when people step forward and step together. The ALS association has given us support, help, a community, an army to stand with and a direction to fight in. I volunteer for my Uncle Steve Stern who exemplifies perseverance and grace in the fight for his life. Volunteering does not sound like a big thing on its own, but the impact of individuals rallying together to fight are vast and far reaching. I am showing up. It is an honor to fight this fight with my family and the ALS association.”

“Together we will fight for the saving of many lives.” Fight we will, Megan. Thank you for being such an integral part of our village of volunteers.
We Walked. We Rolled. And Now, We Thank You!

Each year, the ALS community gathers and rallies around our national signature event, the Walk to Defeat ALS®. Hundreds of walks take place across the nation, raising crucial funds to support local care services, international research projects and remarkably effective public policy initiatives. We are all part of a powerful community of support and together, you make a difference.

Our local chapter holds six Walk to Defeat ALS® events each September, and just within Oregon and the six counties of Southwest Washington, thousands of people gathered together and raised over $645,000!

See below for a recap of the Walk event in your local area.

Central Oregon Walk to Defeat ALS®
Saturday, September 7th, 2013

For our first Walk of the season, the Central Oregon Walk to Defeat ALS® surely was a hit! Blue skies and gorgeous views from Riverbend Park were the perfect backdrop for this uplifting day, which drew over 600 people and raised over $67,000 for the fight.

Our 2013 Central Oregon Sponsors:
Precious Byrd
Eberhard Dairy
High Desert Produce
NORCO Medical
Old Mill District
Strictly Organic
The Bend Bulletin

Southern Oregon Walk to Defeat ALS®
Sunday, September 8th, 2013

Hawthorne Park in Medford was bustling with ALS supporters for the Southern Oregon Walk to Defeat ALS®. Our wonderful volunteers cheered on teams both large and small as they came together to fundraise over $23,000.

Our 2013 Southern Oregon Sponsors:
VIP Entertainment
Mercy Flights

State Capitol Walk to Defeat ALS®
Saturday, September 14th, 2013

The State Capitol Walk to Defeat ALS® gathered hundreds of participants at the Oregon State Capitol. Raising over $32,000, the Walk was an inspiring and amazing day.

Our 2013 State Capitol Sponsors:
Consonus Healthcare
Salem Hospital
R&J Mobility
Voodoo Doughnuts

Willamette Valley Walk to Defeat ALS®
Sunday, September 15th, 2013

Fun was had by all at our Willamette Valley Walk to Defeat ALS® in Eugene. Teams brought their spirit and The Olive Garden brought lunch, all to the backdrop of wonderful live music and a celebrity appearance by The Oregon Duck. We rallied together to raise $18,000 to help strike out Lou Gehrig’s Disease.

Our 2013 Willamette Valley Sponsors:
Peace Health Medical Group
Oregon Neurology Associates
Voodoo Doughnuts
Dynamix Crew
Olive Garden
PacificSource Health Plans

Southwest Washington Walk to Defeat ALS®
Saturday, September 21st, 2013

Amidst torrential downpours of rain, hundreds of participants rallied at Esther Short Park in Vancouver supporting the most successful Southwest Washington Walk in our chapter’s history. Blowing its goal of $64,000 out of the water, the Walk raised over $84,000! Spirits were kept shining through the raindrops with the help of The Beat Goes On Marching Band.

Our 2013 Southwest Washington Sponsors:
Hartford Funds
RS Investments
Northwest Mobile DJ
Voodoo Doughnuts
Portland Metro Walk to Defeat ALS®
Sunday, September 29th, 2013

With worries of a Pacific typhoon planned to blast the Portland-Metro area the day of the Walk, tension was high. The rain came as planned, as did a bit of wind, but perhaps the most remarkable moment was the number of people who still came out to be part of the event. People were unrecognizable through the ponchos, raincoats, hats and galoshes, but walkers bonded and rallied toward the goal of creating a world without ALS.

Our 2013 Portland Metro Sponsors:
Campbell & Company
DWS
JP Morgan Asset Management
Steben & Co
Steinberg Investment Group, LLC
SunAmerica
Interim Healthcare
Norco
Resmed
Invacare
Motion Concepts
Hill-Rom
Performance Mobility
StyleShock
Northwest Mobile DJ
Voodoo Doughnuts
Columbia Sportswear
Organically Grown
Portland General Electric
KIND Snacks

Many thanks to the following local business members who worked together to raise over $118,000 towards our 2013 Walk to Defeat ALS®.

So much gratitude to Chip Laizure and Fred Shipman with JE Dunn Construction for leading the successful effort.

Leslie Adams * Performance Mobility
Angeline Adler * NORCO Medical
Mary Beth Baker * Fred Meyer
Trina Bandelow * Northwest Medical
Matthew Bassist * Langley Investment Properties
Barry Brewis * Brewis Group, Inc.
Wes Carson * HomeWatch Caregivers
Heather Dailey * Con-way
Dr. Kimberly Goslin * Providence ALS Center
Doug Greenberg * Morgan Stanley
Gary Frayn * ATG
Joseph Gross * JGP Wealth Management Group
Alexis Halmy * Windermere Real Estate
Ray Hobizal * Adventist Health
Tom Holt * Regence BlueCross BlueShield of Oregon
April Hughes Sanders * Wells Fargo
Valerie Hurst * KATU
Sarah Jewett * Interim Healthcare
Liz Johnson * Harder Mechanical Contractors
Dr. Lou Libby * The Oregon Clinic
James Lobdell * Portland General Electric
Laura Michaels * Resmed
Kate Moore * Dunn Carney Allen Higgins and Tongue, LLP
Tim Nay and Sam Friedenberg * Law Offices of Nay and Friedenberg
Michael O’Gara * The Seguro Group Inc.
Ryan Oliver * Oliver Insurance
Jessica Osborn, Kathy Fauria and Brian Monoian * Numotion
Jesse Paull * Hill-Rom
Kristin Quinlan * Certified Languages International
Cindy Romaine * Romainiacs Intelligent Research
Lance Steinberg * Steinberg Investment Group, LLC
Dave Underriner * Providence Health and Services
Stuart Van Riette * Small Parts Manufacturing Company
Chip Wallace * Capital Credit and Collection Service, Inc.
Ted Wiberg * Western Partitions, Inc
A Heartfelt Letter from Colin Miner

Sunday was one of those days that convince people Portland is a grey, miserable city where people exist in a bubble of rain. It was coming down straight, sideways, at times hitting puddles so hard you would not have been blamed for thinking the rain was coming up from the ground. It was not pleasant. And yet, for several hours, I was among some of the most pleasant, content people on the planet.

It was the annual walk put on by the ALS Association of Oregon and Southwest Washington. I was there, as I have been the past several years, to support my father-in-law, John Solomonson. He’s the reason I moved to Oregon.

It was about six years ago and John was visiting us in New York. We were down by Wall Street and he slipped off a curb. For a long time we looked for answers, none of which were ALS. After all, it is not a disease people think of because no good can come from it.

Also known as Lou Gehrig’s disease because of how it killed the Yankee great, ALS robs people of their ability to move and in many cases, their ability to speak, to swallow, eventually, to breathe. Every 90 minutes someone is diagnosed and every 90 minutes someone else dies.

On a regular basis, we get emails from the ALS Association with a subject line reading: sad news. These notes always leave you in tears. We hear about Karen “who had a bright smile and was a lovely person with a great sense of humor.” We learn that “it is with continued sadness that I need to let you know that Marilyn passed away” and how she valued the “friendships she made” at support group.

There was Larry who “was not in distress or any discomfort. He was always willing to share and support others.”

We heard about Linda who “had a bright, positive and practical outlook on living with ALS.”

We heard about Harper who “was an incredibly physically capable man who loved the outdoors, building with his hands, playing sports, developing his career as an architect, being amongst friends and strangers alike, and the prospect of being a dad.”

The thing that is common in all the notes – in every note we get – is that no matter how sad the news, we are always reminded of the person’s positive attitude. And that brings me back to my father-in-law. Not a day goes by I don’t think about John and how he copes.

He is a man who grew up on a farm in North Dakota, served overseas, traveled, raised three wonderful kids and now lives his life in a wheelchair. And he has a more positive outlook than many people without a fraction of his troubles. I’ve had my own share of things I’ve had to deal with recently and it’s easy to let yourself get bogged down.

And then I think of John and realize I need to stop being stupid.

There are many things he has taught me, from coping with stuff to a love of the outdoors and of national parks. If someone had told me ten years ago that I would go out on my Passport to the National Parks and trying to collect as many stamps as possible, I would have laughed.

There he was on Sunday, wrapped up in jackets and a poncho, racing along in his chair at a pace none of us could really keep up with. One of his brothers had come in for the walk.

And he was one of thousands.

As much as it rained, their attitude kept everyone going.

The ALS Association has been here since 2002 and it is really impossible to overstate the role they play for families.

There are so many things they do, from loaning medical equipment to families denied by insurance to working with caregivers, doctors and nurses about how to provide the best help possible. Nothing, though, is as moving and dramatic as the monthly support group where a couple dozen people gather to show each other that they are not alone. It is hard to imagine anything more inspiring.

There is no cure for ALS. It strikes seemingly randomly. Patients are usually between 40 and 70; the average age is 55 at the time of diagnosis though there are plenty of patients younger than 40.

Half the people diagnosed live less than three years which, of course, means half live longer. Ten percent live more than 10 years and then there are people like Stephen Hawking who has lived with it for decades.

My father-in-law has me believing anything is possible.

And that’s why I walked on Sunday. And why I will always walk.

- Colin Miner
Walk to Defeat ALS® participant
Thank you to our 2013 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, Wells Fargo and Numotion
35 New Research Projects Funded

Your donations to research through the chapter are part of $4.3 million in new research granted that were awarded in August 2013. These awards are part of the Translational Research Advancing Therapy (TREAT ALS ™) program, through which The Association funds a diverse portfolio of ALS research to find treatments and a cure for the disease.

“These awards will drive research on several emerging fronts in the quest to understand and find treatments for ALS,” said Lucie Bruijn, Ph.D., Chief Scientist for The ALS Association. “The generosity of our donors and supporters makes these grants possible. We are very grateful for that generosity and the opportunity it provides to make these awards for this important research.” Outside of the regular quarterly support our chapter sends to our National office to fund research, we gave an additional $150,000 at the beginning of this year, thanks to our supporters and last year’s successful fundraising efforts.

The awards will go to scientists in laboratories in 14 states in the United States as well as in the United Kingdom, Ireland, Belgium, Canada, Argentina, France and Italy. These awards will support 35 new research projects. All of these new grants will support research to understand the causes of ALS, to develop new treatments, and to create tools that will help improve clinical trials of new therapies. More specifically, the research will include animal model systems, genetics, stem cells, and work directly with people with ALS.

For a complete list of the research projects funded visit: www.alsa.org/research/

The ALS Association has committed more than $67 million to find effective treatments and a cure for Lou Gehrig’s Disease. Our global research effort has helped increase the number of scientists working on ALS, advanced new discoveries and treatments, and has shed light on the complex genetic and environmental factors involved in ALS.

Supporting Clinical Trials and Patient Access to Research

For the sixth consecutive year, The ALS Association is pleased to announce its support of the Northeast ALS Consortium (NEALS), the largest consortium of ALS clinical researchers in the world. This year’s award totals $500,000 and will fund new initiatives and ongoing programs that will increase the quality and efficiency of clinical trials for ALS. The grant will support the work of NEALS in its collaboration with The Association’s Translational Research Advancing Therapy (TREAT ALS ™) program, a diverse portfolio of ALS research to find treatments and a cure for ALS.

“We are very pleased to continue and extend support for ALS clinical trials research through the collaboration between NEALS and TREAT ALS,” said Lucie Bruijn, Ph.D., Chief Scientist for The Association.

New initiatives funded this year include:

• Exploring the feasibility of a centralized Institutional Review Board (cIRB) for NEALS clinical trials. An IRB is responsible for protecting patient safety and autonomy during a clinical trial. Studies have shown that a centralized IRB can perform the same functions while greatly reducing the start-up time for a trial. NEALS will pursue the possibility of establishing a cIRB for its trials, in order to reduce delays in beginning trials for new drugs. They will also pursue efficiencies in contract development and trials site reporting, both important aspects of running efficient clinical trials.

• Videotaping the annual Clinical Research Learning Institute (CRLI) in an effort to reach a broader patient audience. The CRLI is an intensive program dedicated to educating patients and caregivers on clinical research and therapy development while also empowering them to act as advocates for ALS research. Providing web-based access to the program will offer patients and caregivers unparalleled access to this high-quality and actionable information.

• Creation of a Global ALS Patient Identifier. Using technology from the National Institutes of Health, NEALS will create a unique ID for each ALS patient who enters a clinical trial. This will protect patient identity while enhancing research collaboration. Researchers will be able to share data and biofluids without compromising patient privacy.

• Development of NeuroBANK™, a platform for collaboration, research, education and best clinical practices development utilized by the ALS clinical and research community. NeuroBANK is poised to become central repository for clinical research data in ALS, greatly expanding the ability of researchers to share data and speed research. Samples collected through this resource are available for researchers world-wide.

In addition to these new initiatives, The Association’s support will allow continuation of multiple ongoing projects, including clinical trials recruitment, training of young investigators, and improving the quality of clinical trials through training of both Principal Investigators and Site Investigators.

Funding will also continue to support the ALS Association/NEALS Clinical Trial Expert Line, which offers a full-time staff member to answer questions and help people navigate through the clinical research information. Help is available by telephone at (877) 458-0631 during regular business hours, Eastern Standard Time, or by email at alstrials@partners.org
HONORING OUR VETERANS

Honoring Our Veterans

The ALS Association is honoring veterans with ALS on our Wall of Honor to raise awareness about the alarming fact that people who serve in the military are twice as likely to die from ALS as those in the general population. The Wall of Honor shows the faces of veterans with ALS and tells their moving stories of courage both to fight for our country and against this disease. It currently profiles more than 250 veterans with ALS from every branch of the military and almost every state in the country.

Many veterans don’t know that ALS is designated as a service-connected disease and that veterans with ALS are eligible for significant health and disability benefits, including monthly compensation, to help them and their families with the medical and financial burdens of the disease. Survivors of veterans who have been lost to ALS also are eligible for benefits, including monthly compensation even if their loved one passed away years or even decades ago.

If you know a veteran with ALS, please join us and ask them to submit their story to the Wall of Honor today.

HOW TO REACH OUR CARE SERVICES TEAM

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Email</th>
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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.

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 more 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](http://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.
SOUTHWEST WASHINGTON
Second Wednesday of every month
4:00pm - 5:30 pm
Southwest Washington Medical Center
Memorial Campus
Fir/Willow Conference Room, Basement Level
(Enter building through Urgent Care entrance,
Take elevator to Basement. Conference room is
to the left.)
100 E. 33rd St. (Just off Main St.)
Vancouver, Washington
For more information and directions contact:
Sarah Greenstein, MSW at 503-238-5559 ext 5.

YAMHILL COUNTY
Quarterly – next meeting in January 2014
Mcminnville Community Center
600 NE Evans St
Mcminnville, OR 97128
For more information and directions contact:
Sarah Greenstein, MSW at 503-238-5559 ext. 5.

STATE CAPITOL AREA
Third Wednesday of every month
3:00pm - 4:30pm
Salem Hospital Regional Rehabilitation Center
Third Flood Conference Room (next to Pediatric Rehab)
2561 Center St. NE
Salem, Oregon
For more information and directions contact:
Mary Rebar at 541-990-1246.

WILLAMETTE VALLEY
Second Wednesday of every month
3:00 pm - 4:30 pm
Hilyard Community Center
2580 Hilyard Street
Eugene, Oregon
For more information and directions contact:
Mary Rebar at 541-990-1246.

SOUTHERN OREGON
Third Thursday of every month
1:00 pm - 2:30 pm
For more information and directions contact:
Gail Gallaher at 541-292-8775.

CENTRAL OREGON
Second Wednesday of every month
11:30am - 12:30pm
St. Charles Medical Center
2500 NE Neff Road
Bend, Oregon
For more information and directions contact:
Betsy Paige, LMSW, at 541-977-7502.

Thank you for helping us update our databases.