Because of YOU, we are Chapter of the Year for The ALS Association in 2012.

This award recognizes the chapter within the network of 42 chapters across the United States for the highest level of accomplishment in chapter performance. It honors the outstanding overall performance of all facets of chapter management, significant revenue growth, impact of patient programs and care services and exceptional operational standards.

"There are few words to describe the pride that we have in the extraordinary efforts that thousands of people in our region have put forth to place our chapter to be in this esteemed position. Together, our hard work is creating the necessary change we want to see for the ALS community," said Aubrey McCauley, development director for the local chapter. "Our work is not done, but we have sincere confidence that we are well on our way to where we want to be."

Be one in a million.
Help us raise $1 million. Are you in?

We all have our reasons that we pick up our newest edition of The Voice and turn the pages. Maybe you read it because it reminds you that you're part of a remarkable community of support for people touched by ALS. You get excited learning about local opportunities to get involved. You look forward to reading about our top-notch research updates or accomplishments in public policy. You're interested in the profiles of each care services coordinator and look forward to their own updates. Whatever the reason, the common reason we all read The Voice because we care.

Whether it be one reason, it's important. Your motivation is ALS and helping The ALS Association take steps to find a cause, treatment and a cure. And, remarkable steps are being made. This year, we're not just stepping. We're leaping.

Help us raise one million dollars to help the fight against ALS. Be part of one of our events this year, and collectively, we will reach this landmark.

Ski to Defeat ALS – April 13th at Mt. Hood Meadows

Ride to Defeat ALS – July 13th in and around Mt. Angel, Oregon

Walk to Defeat ALS® - Throughout September across our region.

To register or for more information, visit OneMillionForALS.org or call 800.681.9851 x2 today!
Chapter makes an extraordinary $150,000 gift to research.

Our chapter contributes regularly and generously to fund the National ALS Association Research Program. This support happens on an ongoing and regular basis every quarter.

As we ended 2012 celebrating our 10 year anniversary, we are thrilled to share that our board of directors finished off the year with an extra exclamation point. In recognition and response to our board’s extra effort, they approved an extraordinary gift of $150,000 towards the mission to find a cure for ALS! This additional gift is possible because of you! You came out in force in 2012 as a community to support our efforts through our annual gala, Walk to Defeat ALS®, Ski to Defeat ALS, Ride to Defeat ALS, as well as through third party events and personal and planned giving. You generosity made this extra effort possible.

The National ALS Association TREAT ALS effort to fund the development of new therapies is currently funding two clinical management grants, three drug discovery contracts, two clinical pilot studies and three biomarker studies. Currently, the TREAT ALS® portfolio has 80 active research projects with a total award value over $12 million.

This $150,000 adds to this effort. We are proud and honored to be able to make this contribution. Thank you all for your support, you made this possible.

In recognition of those who have saved 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.)

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 United Seating & Mobility.

Our inventory of equipment consists of over 500 items including manual and power wheelchairs, bath seats, patient lifts, and even, a beach wheelchair. United Seating & Mobility 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 United Seating & Mobility ensures our families receive free support while waiting for insurance coverage or when various DME products are not covered by their insurance plan.

United Seating & Mobility 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.

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

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

Ronald Anderman, Judy Austin, Jim Baker, Regan Carter, Chris Cole, John Condon, Ted Eberhardt, Steven Forsyth, Dee Gomes, Eugene Harris, Mark Harris, Gerald Helms, Sandra Henry, Mary Irwin, Jack Lounam, Dave Martin, June Meyer, Susan O’Brien, Tamara Sue Oviatt, Dennis Payne, Steven Rintala, Peter Scott, Colin Slade, Douglas Strautz, Cynthia Tangerud

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 acknowledgment of the gift is sent to the person or family designated.

The ALS Association has made every effort to ensure the memorials, tributes, and donations are properly recognized and correctly spelled. We apologize for any errors and ask you to call us at 1-800-601-9051 with corrections to our records can be changed and updated.

THANK YOU TO OUR 2013 YEAR-ROUND PARTNERS

Central Oregon
Regional Services Coordinator
Betsy Paige, LMSW
541-977-7502
e-mail: BetsyPaige@alsa-or.org
The ALS Association
P.O. Box 1855
Bend, Oregon 97709-9998

Southern Oregon and Willamette Valley
Regional Services Coordinator
Gail Gallaher, M.Ed.
541-292-8776
e-mail: GailGallaher@alsa-or.org
The ALS Association
2305 Ashland Street, Ste C, Box 458
Ashland, OR 97520

FROM THE OFFICE

THANK YOU TO OUR 2013 YEAR-ROUND PARTNERS

Alpenrose Dairy, Fred Meyer, Northwest Medical, Wells Fargo and United Seating & Mobility

FROM THE OFFICE

Thank you to our 2013 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, Wells Fargo and United Seating & Mobility.
NW Oregon & SW Washington

It has been a busy winter in the Portland Metro and SW Washington region as we continue to support many newly diagnosed individuals and their families through engaging them with resources, community and hope. Through home visits, clinics, support groups and much phone support we continue to address important issues with families at every step of their journey with ALS, including legal and financial planning for the future, durable medical equipment needs, caregiving and respite, and social support.

Our November Family Caregiver Support Group took the opportunity during National Family Caregivers Month to honor the nine caregivers in attendance with chair massages and festive appetizers as a small token of gratitude from The ALS Association for all of the hard work, care and dedication that caregivers commit to in supporting their loved one living with ALS. It was a beautiful afternoon where the power of connection was tangible and group members had the chance to socialize and take a short, but much needed, break.

Our December support groups were a testament to the living, loving and laughing that people and their families living with ALS continue to engage in while battling the challenges the disease brings. The holiday potlucks allowed everyone an opportunity to mingle and establish stronger social bonds. It also created a safe space to acknowledge that living with a chronic, progressive illness can make the holidays bittersweet as celebrations tend to require adjustment and emotions can be heightened.

Our quarterly Yamhill County ALS Support Group met in late January as well and included a great mix of PALS and their support people ranging from spouses to paid caregivers to siblings. The diversity of perspectives in caregiving and decision making processes were very eye opening for the whole group.

Our assistive technology coordinator, Shana Tognazzini recently attended the International Symposium on ALS in Chicago, where she enjoyed networking with other ALS chapters and hearing about the current research happening in the field of ALS. Home visits, support groups, and networking between ALS teams and community services are always Shana’s priority, and she has been busy working individually with PALS in Oregon and SW Washington. In the spring, Shana also plans on attending the International Technology and Persons with Disabilities Conference in San Diego. This conference, known as CSUN, is where researchers, exhibitors practitioners, and AAC users come to share knowledge of assistive technology. Shana is where researchers, exhibitors practitioners, and AAC users come to share knowledge of assistive technology. Shana is excited to explore the new products and ideas, so that she can come back and share what she discovered.

In addition to all these activities, the past few months brought exciting new developments in local ALS Care and Support. With the support and collaboration of The ALS Association, Kaiser Permanente Sunnyvale has begun to facilitate a monthly ALS Clinic serving four patients per month. This has been a great opportunity to expand ALS services in the area. Additionally, new collaborations with ALS services coordinators at the Veteran’s Administration promise to yield more cohesive care and services to our veterans living with ALS.

Central Oregon

Central Oregon is proud to be able to serve local PALS with ALS and their families. The Central Oregon Clinic is lead by Dr. Ugalde, Physiatrist at The Center and is staffed by talented clinicians from the community. Our first clinic of the year was in January and the next scheduled clinic will be March 8, 2013.

Regional Service Coordinator, Betsy Paige continues to visit and support PALS and families in their homes, leads the monthly support group, participates as clinic social worker and connect people with the ALS Loan Closet as well as other community resources. Betsy also coordinates quarterly caregiver luncheons that are designed to allow the caregiver some time to re-energize, maintain social connections, get some emotional support and brief respite from the challenges and stress of caregiving. Our November luncheon honoring “Caregiver Appreciation Month” was well attended.

The ALS Support group meets monthly, the second Wednesday of each month at St. Charles Medical Center. This group which includes people with ALS as well as caregivers, friends and family of those with ALS is a dedicated and loyal group which welcomes newcomers. Shana from the Portland office was able to join us in November and provided a detailed overview of various assistive technology options available to PALS and even allowed members of the group to demonstrate how they work. Laura Long, Transitions Coordinator from Partners In Care joined us in December for some holiday refreshments while describing the services offered by the Transitions program. Transitions coordinators meet with medically fragile clients to assess need and then refer clients to needed services or a Transitions volunteer. Volunteers are not caregivers but friendly visitors who may assist with light housekeeping, errands and companionship. We are looking forward to welcoming other members of community groups in the next few months including Volunteers in Action, the local Fire Department and the St. Charles Medical Center Lifeline office.

Southern Oregon/Willamette Valley

Gail Gallaher, Regional Services Coordinator for the Southern Oregon and Willamette Valley regions, continues her support of people and their families living with ALS. Support groups in both areas are active and welcoming new members. The compassion, humor, information and encouragement shared by members create an upbeat and constructive experience. Visiting speakers at groups in recent months include our board member, Trina Bandelow and Ellen Downes, occupational therapist. We are able to arrange for snacks for baking and sharing our trademark goodies for meetings.

Outreach to the medical community remains a priority. Gail has visited neurology and pulmonology practices, therapy and home health agencies, and disabled services providers. She is always eager to speak to community organizations and service clubs to raise awareness about ALS and our chapter services.

During January, our community partners at the Medford Eagles Lodge hosted a series of fund raising events. Their successful outcome ensures the continuation of an emergency fund for local PALS who need help with out-of-pocket expenses not covered by insurance. Special thanks to Betty Johnson and Rae Eatherton who produced the events and who also provide a monthly luncheon at the lodge. Over many years, since a fellow lodge member contracted ALS, Betty and Rae have maintained their commitment to supporting families with ALS. Computer and van repairs, tires and brakes, air fares for a long overdue family visit, and home medical supplies are a few of the expenses covered by the fund. We extend our gratitude to Betty and Rae for their heartfelt support.

In honor of National ALS Awareness Month, Gail will host a Celebration of Life gathering on Saturday, May 4th from 2:00 to 3:00 p.m. at the Medford Library. Music will be provided by harpist Bonnie Walker. All are invited to bring photos and flowers for the memory table, and to share stories about their journeys living with ALS. This annual gathering continues to be an uplifting event with much laughter and gratitude, a few tears, and a spirit of comfort and community.

Welcome Mary!

We are happy to announce the arrival of a new Regional Services Coordinator to the Willamette Valley Region. Mary Rebar has transferred from The ALS Association Everett Chapter to join our team.

Mary has served people living with ALS in Alaska and the North Sound region of Washington for the past five years at the Everett Chapter. She brings a passion for serving families on the journey with ALS. She has coordinated four monthly support groups, including a virtual support group. One of the highlights of her position was a trip to Alaska that included travel by ferry to visit families on the San Juan Islands.

Mary is returning to the Willamette Valley to be near extended family. After graduating from University of Portland, Mary has lived in four states and two countries. The job that was most challenging for Mary was teaching English in Hadano, Japan. One of her favorite positions involved working for Access Alaska, an Independent Living Center, where she assisted with education on the Americans with Disability Act (ADA).

With two adult sons, Mary and her husband enjoy outdoor adventures and cheering at the soccer fields. Mary relishes family time including playing board games and Legos. Mary enjoys Tai Chi, fishing, and weekly visits to the local library in order to stock up on books, magazines, videos and other educational materials. Finally, Mary enjoys learning about the art of Tea including the cultivation of tea leaves.

Mary looks forward to meeting families in the Willamette Valley.

Please join us in welcoming Mary to our team.
The Value of Support Groups

Our ALS Support groups in Oregon and SW Washington bring people together to learn about ALS symptom management, connect with others with ALS, and experience the shared challenges of the disease. The community aspect of these groups can provide a sense of belonging and support, helping individuals and families cope with the emotional and physical changes associated with ALS.

“I attend the support group in Yamhill County. My diagnosis is ALS so at first I felt awkward as my difficulties were not as severe as those with ALS. Though my path is slower and less certain, I too am losing my ability to move as I navigate an almost completely altered life. The people I have met in our group continue to amaze me with the love and grace they radiate in the throes of this disease. When I see how they rise above their circumstances, it helps me to know I can too.”

Joan Steinfeld

“I suppose the best thing is being aware of others that are living with ALS and hearing how they are doing it. Always good to know that you are not alone…”

Tom Hendricks

“I attend both the Portland and Vancouver groups because I love the people in both of the groups. And I think they kind of like me as well. The meetings give and gain. Ideas, ideas, ideas, a chance to see what works for others. It really helps knowing that I’m not going through this by myself. The different guest speakers and the Association staff have so much to offer and are so helpful. It supports us all.”

Brian Epp

If you or your loved one has never been to a support group, but are considering it, we encourage you to give it three chances. The first time can be overwhelming and full of mixed emotions including sadness, anxiety and fear of engaging with people who have advanced disease progression. The second time, you have a little more of an idea of what to expect and probably have a list of questions you are interested in having answered by the “experts” also living with the disease. The third time, you remember individual people and have been looking forward to seeing their smiling faces again. Our groups are not therapy focused. They are educational and support based. There are always some tears, as is natural when coping with the challenges of a diagnosis like ALS, but there is also a lot of laughter, encouragement, optimism and spirit shared. We encourage you to try it out for yourself to determine if it is a positive coping tool for you. The power of community is strong and the members of this community are kind, welcoming, insightful, caring and will not let you feel like you are doing this alone.

Please contact your local Regional Services Coordinator with questions or to find out more.

New ALS clinic launched by Kaiser Permanente and The ALS Association

Rolling through the door in her power wheelchair, Marilyn Palmer of Portland, OR was the first person with ALS to receive care from the Kaiser Permanente ALS Clinic at Sunnyside Medical Center. “It is an amazing place,” says Marilyn. “I can come to one office and see all the healthcare professionals I need in one spot. Everyone here works together and really wants to help.”

The clinic which held its first session in late 2012 is a exciting new partnership between The ALS Association and Kaiser Permanente NW.

Proactive management of ALS is the primary goal of the Kaiser Permanente ALS Clinic. “We want to find a cure for ALS, but in the meantime we want to make sure everyone diagnosed with ALS has the best possible care and support so that they can live a good life with ALS,” says Jack Stigler, D.O. the clinic’s directing neurologist. “All the professionals on our team have shown that they are deeply committed to caring for people with ALS and are strong patient advocates making sure people with ALS get their needs met.”

At a typical clinic appointment at the Kaiser Permanente ALS Clinic, a person with ALS and their family caregivers will stay in one exam room while a parade of healthcare professionals will cycle through for assessment and evaluation. At each clinic appointment a person will see a neurologist, a nurse, a social worker, a physical therapist, an occupational therapist, a respiratory therapist, a speech language pathologist, an augmentative communication specialist, and at times when it is appropriate, a pulmonologist.

“A visit to the Kaiser Permanente ALS Clinic can potentially condense the need for a dozen separate appointments into one visit.”

Caring for a person with ALS is more than a full time job. Doing it alone is a hard path to walk. Many people find by sharing the care with friends and family the journey with ALS becomes easier.

The ALS Association Oregon and SW Washington Chapter provides free copies of the Share the Care™ book to people with ALS and their families in Oregon and SW Washington. In addition, our professional services staff can work with you to create your own Share the Care™ group.

To learn more, please contact your regional services coordinator or our main office at 800.681.9851 and info@alsa-or.org.
Navigating the Future for ALS

When facing a diagnosis of ALS, a disease more commonly known as Lou Gehrig’s Disease, the questions are endless, the terrain unknown, and ever-growing needs overwhelming. Because of supporters like you, The ALS Association Oregon and SW Washington Chapter can be their navigators, champions, advocates, and confidants.

Since 2002, our local chapter has empowered those living with ALS to realize that even with a disease that on average only gives a person two to five years to live; one can live their remaining days to the absolute fullest.

Because of supportive community members, all of this is given without costing the families a dime. The ALS Association Oregon and SW Washington Chapter’s annual Dinner and Auction Gala has raised over $2.5 million since the chapter’s inception.

On Saturday, March 9, 2013, in the Oregon Ballroom at the Oregon Convention Center in Downtown Portland, Oregon, there will be well over 500 guests participating to raise an additional $300,000 towards this collective effort.

Join the fun! Corporate Sponsorship Opportunities, Various drawings, Wine Grab Bags, Silent Auction, Live Auction, Paddle Raise, Restaurant and Dessert Frenzies, and much, much more!

Various ways for all to participate, all to make a difference!

**Auctioneer:** Graham Crow, Benefit Auction Associates

**Emcee:** Tracy Barry, KGW Anchor

**Keynote Speaker:** Bo Stern, ALS caregiver & author of Beautiful Battlefields

**Entertainment:** The Dan Balmer Trio featuring Mel Brown

**www.ALSgala.org**

503-238-5559 ext 3
gala@alsa-or.org

This event is currently sponsored by:


Thank you April Candidora

April Candidora is everything you could ask for in a volunteer and so much more. Not only does she fit all of our basic volunteer needs, she’s responsible, timely, and committed to the cause. She’s also friendly, fun, and outstandingly hard-working. Her dedication to the ALS Association consistently goes above and beyond the call of duty, a trait that seems to run in the family. Her two wonderful daughters, Taylore and Samantha, are also known for their above and beyond volunteer service, going so far as to spend birthdays volunteering with us. It’s not often that you find young kids that are willing to forfeit time with their friends to do something selfless and important for the community. It can only speculate that having a mother and role-model like April had something to do with it.

**Welcome Anna Holmes!**

We are delighted to introduce our new Events and Volunteer Coordinator at The ALS Association Oregon and SW Washington Chapter.

Anna is originally from Los Angeles California and moved up to Portland to attend school at Lewis & Clark College, where she earned degrees in Political Science and Foreign Language. In her last year of school at Lewis & Clark, she started working at the school’s office of Alumni & Parent Programs, where she had the opportunity to be a part of many different types of events and worked with some really wonderful people. After graduating from Lewis & Clark last May, she worked at the Alumni Office for a couple extra months as a Reunion Weekend Coordinator and then finally her time at Lewis & Clark came to a close. Since then, she has spent some time working at the World Affairs Council of Oregon in their International Visitor Program department. She also worked as an event coordinator at Entercomm, a communications agency that runs select radio stations in the Portland area.

“I can tell already that the best is yet to come. I am so excited to be a part of this really special community that supports those affected by ALS.”

In her spare time, she enjoys cooking, hiking, reading, and spending time with her friends and family.

Upcoming Volunteer Opportunities

We have many exciting volunteer opportunities coming up in the next couple of months. Whether you’re a cyclist, a skier, or just like to be wired and dined, we have a job for you! Find below a complete list of ways you can help.

**Community Booths:**

PDX Bicycle Show
March 23-24 – Expo Center – Portland, OR

**Chapter Events:**

- Ski to Defeat ALS Kick-off Party
  **Sunday, March 3 – Copper Monkey Event Center – Beaverton, OR**
- **ALS Dinner & Auction Gala 2013**
  **Saturday, March 9 – Oregon Convention Center – Portland, OR**
- Ski to Defeat ALS
  **Saturday, April 13 – Mt. Hood Meadows – Mt. Hood, OR**

- **Alumni & Parent Programs**

- **Spring Break Rendezvous**
  **March 17-18 – Mt. Hood – Government Camp, OR**

- **Eugene Walk to Defeat ALS**
  **April 20 – University of Oregon – Eugene, OR**

- **Portland Walk to Defeat ALS**
  **April 21 – Timberline Lodge – Government Camp, OR**

**Volunteer Opportunities**

- **Best Western Portland Airport**
  **April 11 – Portland, OR**

- **Volunteer Opportunities**
  **April 12 – Oregon Convention Center – Portland, OR**

- **Volunteer Opportunities**
  **April 19 – Oregon Convention Center – Portland, OR**

- **Volunteer Opportunities**
  **April 20 – Oregon Convention Center – Portland, OR**

- **Volunteer Opportunities**
  **April 21 – Oregon Convention Center – Portland, OR**
We Walk because we can. We Walk for love, for hope, for services, for research and for ultimately, a cure. We Walk for those who can’t. We Walk because we can. Each year, our local chapter holds six Walk to Defeat ALS® events throughout our area of Oregon and SW Washington. Each event is different and special in its own way, but each one promises one thing: we’re all in this fight together. We’re all part of an empowering community of support, and everyone who participates in any of the Walks not only in Oregon and SW Washington, but across our country knows exactly what ALS is all about and what it feels like to feel powerless against it. The Walk is one way that we can be powerful. We can make a difference. We can and we are.

Can’t join us at one of our events? Consider participating “virtually.” That’s right, if you’re out of town or just can’t make it to the event, contact us to learn more about virtual participation. You will get all of the support as a standard participant, including support from our local chapter, online tools and more. And if you don’t live near one of our events, consider participating this way and holding a walk, ride, or cycling experience where you are!

Did you know?

Each Walk to Defeat ALS® registered participant that raises $25 or more is eligible to receive an official Walk to Defeat ALS® t-shirt on Walk Day!

Teams who register early are almost always the top fundraisers and the largest teams of the year. Why? Signing up early gives friends and family plenty of time to plan and rally.

The Walk is free to participate and is the association’s largest awareness event of the year.

After you sign up, you receive a personal page and incredible resources and tools.

People who sent emails to share their story received on average six more donations then those who didn’t.

Our job is to help take the WORK out of the Walk! Let us sign you up, personalize your webpages and help craft and send your emails. We want to help you be successful in making a positive difference.

Contact us at walk@alsa-or.org or 800-681-9851 ext 2

Mark your calendars!

Central Oregon – Saturday, September 7th – Riverbend Park, Bend
Southern Oregon – Sunday, September 8th – Hawthorne Park, Medford
State Capitol – Saturday, September 14th – Oregon State Capitol, Salem
Willamette Valley – Sunday, September 15th – Park Blocks, Eugene
Southwest Washington – Saturday, September 21st – Esther Short Park, Vancouver
Portland Metro – Sunday, September 29th – World Trade Center, Portland

All Walks open at 11:00 and kick off at noon. Join us this year and join part of this incredible community of support. Join us because you can!

My motivation comes from the strength and courage that my Dad had every day that he fought this disease until he lost his battle this last September! I want to see the phrase “ALS Treatments” replaced with “ALS CURE”

– Jen Helms Lacey, Southwest Washington Walk

Did you know?

Each Walk to Defeat ALS® registered participant that raises $25 or more is eligible to receive an official Walk to Defeat ALS® t-shirt on Walk Day!

Mark your calendars!
Celebrating on the Slopes
Join us on April 13th!

It was just one year ago that the Ski to Defeat ALS broke records. Selling out weeks in advance, it was meaningful, powerful and incredibly fun. One year later, we’re rallying again to hit the slopes of Mt. Hood Meadows and with some exciting updates and changes, raising $150,000 to impact local services, international research and public policy on all levels. If you’re a ski or snowboard enthusiast, don’t let this event pass you buy this year!

When: Saturday, April 13th
Where: Mt. Hood Meadows

What is it? The Ski to Defeat ALS is just a fun day on the mountain. You can participate as an individual, or on a team. A team can be two or twenty people. You can do two runs or two hundred runs. It’s whatever you want it to be.

Details: Participants must pre-register and raise $150 to support the mission of The ALS Association. We have two registration options this year. If you need a lift ticket for the event, the cost is $75. If you have a valid Mt. Hood Meadows Season Pass, the cost is reduced to just $25. Both options include three full meals, an epic day on the mountain, entertainment, two adult beverages, and more! This year, we’ve doubled our capacity from 250 to 500 participants!

And, once again, we’ve partnered with Oregon Adaptive Sports so that a limited number of people living with ALS are able to feel the wind in their faces as they do run after run with the use of an adaptive sit-ski. This was perhaps one of the most memorable moments from the inaugural event.

Participants in this component of the event included people who had never skied before, people who never thought they would be able to ski again, and families who would have never expected to have a mountain experience together. As one onlooker said, we celebrated movement.

How to get involved: Visit www.SkiToDefeatALS.org or call Meagan Lancaster, fundraising manager at 800.681.98512 today!

Tony Halford, an avid cyclist lost his mom Judy to ALS. Tony saw the Ride as a perfect opportunity to combine his love of putting the rubber to the pavement and his desire to make a difference in the lives of those living with ALS. He signed his team, Bethany’s Bikers, up for the inaugural event last year. He invited his friends to join him, which was a great fit because they were also cycling enthusiasts. He raised an incredible amount of money and had an incredibly fun time in the process.

About the event, Tony reflected. “It was incredible. We were all so well taken care of before, during and after the event. The route was challenging in parts, and boasted beautiful and diverse landscapes that cut through the farming communities. Plus, the food was the best I’ve ever had during an endurance ride.”
Below are individuals, corporations, and foundations that have joined you in dedicating themselves to the fight against Lou Gehrig’s Disease. We would like to honor all of you by simply saying THANK YOU.

You all have demonstrated hope, strength, determination, and courage... and all are inspirations to each and every person in our community that is touched by ALS.

Our Heroes: $300,000+
Mr. Jon Buccola

Our Inspiration: $100,000 - $299,000
The Kenneth and Jane S. Libby Foundation
Alpenrose Dairy
Dr. Louise and Barry Kremkau
Our Hope: $25,000 - $99,999
Tina and Jeff Bandelow
Mr. Jerry Nudelman
Northwest Medical
P.M.E. LLC & Peter Perrin
Dr. Kimberly Goslin & Thomas Gazzola

Our Courage: $15,000 - $24,999
Jessie and Mac Butler
Party Overland & Irish Oaks Farm LLC
Traci and Doug Greenberg
Community Health Charities of Oregon
Susan and Robert Sall
Yvonne and Tony McGavoy
Cynthia and David Greene
Cheryl and Nick Ragnone
Gerding Edlen Development Co.
Ann and Mark Edlen
Maggie Bagnall
 Mentor Graphics Foundation
Ms. Milli Davis
Mr. Joseph Speight
Ms. Mary Beth Baker
Vera and Earl Cherry
Ann and Tom Mercer
Ms. Chera-Lynn Roberts
Terrapin Events, Inc.
Western Communications: The Bulletin
Ms. Patrice Boone
Debbie and Kenneth Willett
Dunn Carney Allen Higgins & Tongue
Wells Fargo Community Development
Colliers International
Pacific Northwest Properties
Phyllis and Carl Cadonau
Pink Martins, Inc.
Jessie and Terry Shields
Marianne and Colin Slade
Mr. John Ermaninger
Claudia and Doug McClure
Judith and Paul Newman

Our Strengths: $10,000- $14,999
Stewart Sokol & Gray, LLC Attorneys at Law
Dana and Anita Cadonau-Husby
Mary and Lance Steinberg
Realty Trust Group
Kelly and Bruce Witherupson
Mr. Michael Gross
Ms. Elizabeth Bowman
Alexis Halmy and Alfred Lee
Barbara and James Lohdell
Courtney and Blake Singer
Laurie Chadwick and Lee Mercer
Libby and Michael Crawford
Rose City Classics
Tori and Mark Hanna
Linda and Peter Barty
Francine and Arne Gray
Paula and Mark Foat
Ms. Arlene Anderson
Nike Employee Matching Gift Program
Helen John Foundation
Mr. Matthew Wergen
Ms. Elizabeth “Betsy” McCool
Mr. Jack Hopkins
Nancy and Michael Phillips
Mr. John Alexander
Oregonian Publishing Co.
ATG Rehab
Cheri and James Beatty
Stacey Mooy and Lance Christian
Ms. Barbara Adler
Anne and Scott Weaver
Harry & Dorothy Murphy Foundation
Kayrin Perkins and Jon Westcott
Reser Family Foundation
Kathy and John Connors

Les Schwab Warehouse Center, Inc.
The Wells Family Foundation

Our Determination: $5,000- $9,999
Kristyn and Matthew Bassit
Mr. Timothy Wallace
Mr. Jerome Waterbury
Portland Monthly Magazine
Mr. Christopher Killgore
Langley Investments (Ashforth Pacific, Inc.)
Janice and Richard Romano
Ms. Angie Otto
RE/MAX Equity Group Inc.
Providence Brain Institute
PGE Employee Giving
Ms. Mary Lou Gurnis
Melissa and Michael Haglund
Mr. Don Adler
PacTrust
Carla and Steve Forsyth
Betsy and Michael O’Gara
Ms. Shirley Lefkowitz
Korinn and Steve Weeks
Arleen and Donald Walton
Cindy and John Nobriga

For the purposes of this listing, only total cumulative monetary donations have been listed as of 12-21-12. Names in italics denote those generous individuals who are no longer with us. If your name has been inadvertently omitted or listed incorrectly, please accept our sincerest apologies and contact our office immediately at 800-681-9851 ext 3 or by email at info@alsa-or.org.

Thank you to our 2013 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, Wells Fargo and United Seating & Mobility
Many thanks to the following companies and organizations who match their employees contributions to our chapter:

- AIG Matching Grants Program
- Allstate Giving Campaign
- Amgen Foundation
- ARRIS
- Autodesk Matching Gifts Program
- Bank of America Matching Gifts
- Bank of the West
- BenefiHelp Solutions
- Bristol-Myers Squibb Foundation
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- Costco
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- MA Mortenson Company
- Mentor Graphics Foundation
- Meyer Memorial Trust
- Microsoft Matching Gifts Program
- Morgan Stanley
- Nike Employee Matching Gift Program
- Novartis Foundation
- Pacific Power Foundation
- PepsiCo Foundation Matching Gifts Program
- PGE Employee Giving Campaign
- PNC Foundation
- Reader's Digest Foundation
- Regence Employee Giving Campaign
- SanDisk Corporation
- Starbucks
- Tektronix Foundation Matching Gifts Program
- The Boeing Company
- The GE Foundation
- The Home Depot Foundation
- The ODS Companies
- The Prudential Foundation Matching Gifts
- The Standard Employee Giving Campaign
- Thrivent Financial for Lutherans Foundation
- Travelers Community Connections
- Trust
- United Technologies
- US Bancorp Foundation
- Wachovia Foundation

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The Standard Employee Giving Campaign
Thrivent Financial for Lutherans Foundation
Travelers Community Connections
Trust
United Technologies
US Bancorp Foundation
Wachovia Foundation

A Simple Way to Make a BIG Difference

A legacy gift through your will or living trust to The ALS Association can make a big difference in the fight against ALS. 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 ALS Association
Oregon and SW Washington Chapter
Lance Christian, Executive Director
info@alsa-or.org    800.681.9851

Many thanks to the following employees who have taken advantage of their workplace matching programs:

- Joanne Abbey
- Susan Axelro
- Christopher Anderson
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- Kelsey Asuncion
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- John Nohegta
- Stuurt Parsons
- Teresa Pastorino
- Kayvinn Perkins
- Katherine Petersen

Thank you to our 2013 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, Wells Fargo and United Seating & Mobility
Researchers funded by The ALS Association have discovered evidence of an unexpected cellular process in some people with amyotrophic lateral sclerosis (ALS). The results should allow researchers to better track the disease in these people and may offer a new target for developing therapy.

The research showed that mutations in the C9ORF72 gene cause cells to create an unusual protein-like molecule that is not found in healthy individuals or in people with other neurologic diseases. Mutations in the C9ORF72 gene are responsible for between 20% and 40% of familial ALS. The mutation causes cells to create long, repetitive chains of a cellular molecule called RNA. The researchers found that when the cell’s protein-making machinery latches on to this repetitive RNA, it creates a protein-like chain called a RAN-translated peptide, which the researchers have termed C9RANT. The peptide’s own repetitive structure makes it stick to itself, and the researchers found clumps of the peptide in the brains of people who had died of ALS.

It is still unknown whether these peptides are contributing to disease or are uninvolved in it. But in either case, they offer researchers a specific marker for ALS caused by the C9ORF72 gene and potentially a way to measure disease activity and response to therapy.

“This discovery highlights the complexity of the ALS disease process,” said ALS Association Chief Scientist Lucie Bruijn, Ph.D. “But it also may provide a new window into that process and offer a way to track how neurons are responding to treatments in this form of the disease. In that respect, this finding could be an important step forward.”

The study was conducted by Peter Ash and Kevin Bieniek under the guidance of Leonard Petrucelli, Ph.D., of the Mayo Clinic in Jacksonville, Fl., and was published in the journal Neuron. The ALS Association provided support for this research to Dr. Petrucelli and to Kevin Boylan, M.D., also of the Mayo Clinic and also an author in the study.

“Just as new therapies are being developed to break down the protein aggregates associated with Alzheimer’s and Parkinson’s diseases, developing a therapeutic strategy to target C9RANT aggregates may also prove beneficial,” said Dr. Petrucelli, Chair of Neuroscience.

For more cutting edge information about ALS research visit www.alsa.org/research

Unexpected Discovery Could Indicate New Target for ALS Therapy

Would you like to help bring new treatments for ALS from the lab bench to the patient’s bedside? If so, The ALS Association invites you to help advance the search for treatments as the entire ALS community unites in Washington, DC on May 8 – 11, 2013 for the National ALS Advocacy Day and Public Policy Conference. The conference will empower you with the tools you need to advocate for policies that are specifically designed to accelerate the development of treatments for ALS.

Developing a treatment for ALS is a long process, which begins on the lab bench with basic research and, 15 or more years later, ends with FDA approval. It is an expensive process, which can cost more than $1 billion. The public policy priorities we are advocating in Washington were strategically chosen because each priority, the National ALS Registry, the ALS Research Program and the MODDERN Cures Act, helps to overcome the challenges of treatment development. Ultimately, they may help us find the cause, treatment and cure for ALS.

In order to succeed in getting Congress to act on these issues, we need your active participation in Washington. Members of Congress must understand not only how devastating this disease is, but also what they can do about it; how Congress can help find a treatment for a disease that has gone more than a century without one. And with Congress looking to slash spending more than ever before, your participation this year is absolutely critical.

If you would like to attend or plan on attending this conference, please contact LanceChristian@alsa-or.org.
The Voice
Bringing you the latest news on fighting Lou Gehrig's Disease in Oregon and SW Washington.

SUPPORT GROUP SCHEDULE

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

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

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

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

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

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

Southern Oregon
2nd Wed. of every month, 11:30am - 12:30pm
Rogue Valley Medical Center Campus, Smullin Center, 2825 East Barnett Rd, Medford.

3rd Thurs. of every month, 2:00pm - 3:30pm
Note: this group is for family caregivers only.
Rogue Valley Medical Center Campus, Smullin Center, 2825 East Barnett Rd, Medford.

2nd Tues. of every month, 1:00pm - 2:30pm
Note: this group is for family caregivers only.
For more information and directions contact: Gail Gallaher at 541-292-8775

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

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.