DID YOU KNOW?

• In 2013, over 6,500 people walked to support local services in Oregon and SW Washington. Let’s aim to make this closer to 10,000 in 2014.

• The Walk to Defeat ALS® has raised over $3.5 million dollars for our chapter since 2002. Let’s push this past $4 million in 2014.

• Since 2000, the Walk to Defeat ALS® has raised close to $188 million dollars nationwide! Let’s do our part to push this past $200 million in 2014.

• Anyone and everyone from around the world can be a part of our efforts! Anyone, even kids and your furry friends, can participate. Think globally, act locally.

• The number one reason why people give is because they are asked. Let us help you get your story out.

• Every 90 minutes someone in the United States is diagnosed with ALS. Every 90 minutes, someone loses their battle. Time is of the essence when it comes to the fight against ALS.

Contact us today to learn how you can walk to defeat ALS!

walk@alsa-or.org

(please see inside for dates and more details)
FROM THE OFFICE

OUR ESTEEMED BOARD OF DIRECTORS

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Immediate Past Board President
The Oregon Clinic, LLC

Doug McClure, PsyD
Independent Practice

Kate L. Moore
Dunn, Carney, Allen, Higgins, and Tongue, LLP

OUR DEDICATED STAFF MEMBERS

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Executive Director, Social Worker
LanceChristian@alsa-or.org

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Development Director
AubreyMcCauley@alsa-or.org

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Assistive Technology
Services Coordinator
ShanaTognazzini@alsa-or.org

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GailGallerah@alsa-or.org

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Services Coordinator – Willamette Valley
MaryRebar@alsa-or.org

Betsy Paige 541-977-7502
Services Coordinator – Central Oregon
BetsyPaige@alsa-or.org

Rachelle Preston, MSW
Services Coordinator – Portland Metro
RachellePreston@alsa-or.org

Rebecca Pace
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RebeccaPace@alsa-or.org

Julia Mayfield
Development Manager
JuliaMayfield@alsa-or.org

Maggie Pimm
Bookkeeper and Operations Coordinator
MaggiePimm@alsa-or.org

Thank you again to our 2013 Top Fundraising Teams across Oregon and SW Washington:

Team Kyte – Portland Metro - $31,840
BB – Portland Metro - $18,205
Freddy's Walkers – Portland Metro - $16,235
Team Crawford – Portland Metro - $14,761
Arne's Warriors – Portland Metro - $13,650
Akhil's Angels – SW Washington - $11,715
Dee’s Wing Walkers – SW Washington - $9,751
Ran's Fans – SW Washington - $9,235
For the Love of Eric – SW Washington - $6,490
Robin’s Rockin Family – SW Washington - $4,890

We welcome them and all of you to join us this September as we continue to defeat ALS!
Get out your wheelchairs, walkers and walking shoes! Lets walk... and roll!

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:

February 1, 2014 – May 25, 2014

Patricia Belcher
Mary Hammond
Judith Newman
Ron Warmanen

Jule Bissett
Robert Hawkins
William Newton
Penny Williams

Robert Bohlman
Thomas Hendricks
Sallie Osteen
Jo Ann Yandell

Edward Clark
Jim Koelling
Dennis Payne
Ted York

Betty Cook
Randy Kyte
Virginia Rattay
Katherine Yuen

Mike Dallum
Barbara List
Azusa Suzuki
Ronald Zahm

Roger Doyle
Scott Mather
Steven Turner

Orville Furber
Claudia McNeil
Lisa Turpel

Bill Gabel
Kalan Morinaka
Jocelyn Tuthill

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 800-681-9851 ext 103 with corrections so our records can be changed and updated.

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FROM THE OFFICE

Farewell from Care Services Director, Sarah Greenstein

I want to take a minute to thank each of you for the incredible opportunity to have served as your Services Coordinator and then Care Services Director over the past three plus years. It has been an experience that has truly impacted who I am both personally and professionally. The power of our community is tangible, and I want to acknowledge all of our PALS and family members, incredibly dedicated staff and board, our clinic team members and community partners for making this happen. As our theme from this year’s gala highlighted, it takes a village to fight ALS and it’s been an honor to be part of that village.

It has been truly humbling to witness the raw courage, grace and perseverance with which families face the challenges that ALS brings. I will miss the laughter and the tears that each support group inevitably brings, as well as the gift of time spent in your homes and at clinic navigating those challenges together.

I will leave with the inspiration that you all provide and with a big imprint of this community on my heart. Thank you.

Open Position:

We are seeking a dynamic individual to lead our Care Services Team as Care Services Director. Full-time position with some travel, weekends and nights. 3 years progressive management experience required, and Oregon LMSW or LCSW preferred.

For more details, please visit www.alsa-or.org. Cover letter and resume to LanceChristian@alsa-or.org. **Please no calls or mail.**

In Memory of Our PALS February 1, 2014 – May 25, 2014

Lois Burns
Nicholas Carter
Karen Chinn
Mark Christman
Edward Clark
Thomas Cox
Dianne Demers
Janice Epstein
Randy Erickson
Orville Furber
Mabel Goughler
Mary Hammond
Kimmberly Harthill
Arnold Imbach
Sandy Jumonville
Gretchen Leslie
Barbara List
Michael Lytton
Joyce McMahon
David Mischak
John Neill
Fred Noble
Sallie Osteen
Richard Powers
Noreen Riddle
Artemio Rojas
Margaret Simpson
Cheri Snyder
Kathleen Strait
Azusa Suzuki
Penny Williams
Michael Woldridge
Katherine Yuen

(These lists are based on chapter notifications; please notify us of any omissions or errors.)

OUR ESTEEMED ADVISORY BOARD MEMBERS

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THANK YOU TO OUR 2014 YEAR-ROUND PARTNERS

Thank you to our 2014 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, JGP Wealth Management, Wells Fargo and Numotion.
**Update from Shana Tognazzini - Regional Assistive Technology Coordinator**

Shana continues to work with PALS all across our chapter by working with them in their homes, at the chapter office, by teleconference, or at one of several ALS clinics that she attends.

Shana recently presented for the Southern Oregon and Eastern Oregon support groups about the Augmentative/Alternative Communication and Assistive Technology program for the chapter. She worked in conjunction with the chapter’s Regional Service Coordinators in order to visit with PALS and their caregivers and serve their needs.

Shana also presented on AAC/AT interventions for Speech Language Pathologists in Southern Oregon, Eastern Oregon and the Portland areas. Her goal is to increase AAC/AT awareness and comfort for professionals serving PALS in our community. She also plans on hosting a graduate student this summer and is excited to share her passion for AAC/AT as a field instructor.

**Update from Sarah Greenstein - Portland/NW Oregon/SW Washington**

In the Portland Metro area, Spring time found care services staff Lance Christian, Sarah Greenstein and Rachelle Preston continuing to serve individuals living with ALS and their families through home visits, support groups, and multidisciplinary clinic representation at Providence, Kaiser Permanente and the Veteran’s Administration. Support groups throughout the region featured Dr. Lou Libby and Jane Albrecht from NW Medical providing our families with a hands on respiratory equipment show and tell and explanation as well as Occupational Therapist Deb Fulkerson with her educational show and tell of helpful tools to assist with activities of daily living.

An annual highlight in our ALS Community is the way we acknowledge the month of May as ALS Awareness month. It is exciting to see the Proclamation from Governor Kitzhaber’s office declaring May ALS Awareness month and to be part of the national movement to bring ALS to the forefront of the minds of decision and policy makers in Washington DC. Thank you to our Willamette Valley Services Services Coordinator Mary Rebar, Tom Holt- Board Member, Dr. Lou Libby- past Board President, PALS Rob Chadwick and Ken Feldhaus (and his wife and daughters) for representing Oregon and SW Washington this year at our National Conference in DC to advocate for our communities greatest priorities. At our local support groups during the month of May we came together to share personal stories, discuss how to talk about ALS with friends and family, and to emphasize the importance of building allies in our communities who know and care about ALS. Also in May, we were proud to present an ALS Research Forum on Saturday afternoon, May 10th. Dr. Kimberly Goslin of the Providence ALS Center, Dr. Joe Beckman of OSU and Dr. David Motlin of OHSU each delivered interesting presentations on their areas of expertise in the research of ALS treatment as well as participated in a panel question and answer session. Thank you to our esteemed presenters for enlightening our community while helping us to understand the scientific process and how to interpret the various theoretical and practical orientations that current trends originate from.

**Update from Mary Rebar - Willamette Valley**

The Capitol Support Group members are enjoying their new meeting room at the Community Health Educational Center on the Salem Hospital Campus. The Capitol Support Group meets the third Wednesday of the month from 3:00-4:30 pm.

In April, the Willamette Valley and Capitol Support Groups discussed the modified clothing continuum. The PALS and families shared ideas and viewed modified clothing options; including shirts, pants and a weatherproof poncho to cover a power wheelchair.

In May, Mary attended Advocacy Day in Washington DC with two PALS and their family members and board members. The Advocacy Day on Capitol Hill was filled with hard work and passion. The following day involved research updates. The first report from the ALS National Registry will be published in June.

**Update from Betsy Paige - Central Oregon**

The Central Oregon ALS Support Group meets monthly at the Bend St. Charles Medical Center the second Wednesday of each month from 11:30 – 12:30. Newcomers are always warmly welcomed by this supportive and well attended group of people. Since the last newsletter, physical therapist JoAnne Bernt joined us and educated us on the importance of range of motion exercises, breath stacking and then even demonstrated how to use various equipment including the hoyer and sit to stand lifts. We also welcomed speech language pathologists Abigail Cary and Emily LePore and the ALS Association’s own Shana Tognazzini who addressed current Medicare funding changes for speech generating devices, as well as demonstrating the effectiveness of voice amplifiers, switches and home alert systems.

Dr. Vivianne Ugalde leads the collaboration of clinicians from The Center, SCMC and Bend Memorial to host a multidisciplinary clinic every other month at The Center. The ALS Clinic welcomes to the clinic team, Eric Ballinger (PT), Abbie Cary (SLP), Emily LePore (SLP) and Tracy Halsey (OT). The next clinics will be held on July 11th and September 12th, 2014.

Central Oregon services coordinator Betsy Paige, LMSW continues her support of families and people diagnosed with ALS through home visits, facilitation of the monthly ALS Support Group and through participation in the Bend ALS Clinic. Betsy also works closely with community partner NORCO to coordinate the Bend ALS Loan Closet (thanks Norco!).
Regional Services Coordinator Gail Gallaher continues her support of PALS and their loved ones through home visits, medical equipment loans, and support groups. Outreach to local neurologists and other medical providers, including home health and hospice teams, remains a priority. Gail attends the MDA sponsored monthly clinics at Providence Medford Medical Center to consult with PALS who are scheduled for appointments. Recent support group speakers include our own Lance Christian with updates on The ALS Association services and current research, and Rebecca Pace on the September 7th Walk to Defeat ALS. Our special ALS Registry volunteer, John Deeming spoke about the importance of the National Registry and offered instruction to new PALS on signing up.

Thanks to the efforts of Medford PALS, Dawn Huttl, Mayor Gary Wheeler proclaimed May to be Medford ALS Awareness Month. Rebecca Pace was invited to speak to the Medford City Council about ALS. To further raise awareness, Gail participated in a live panel discussion of the benefits of support groups on public radio’s Jefferson Exchange.

COMING SOON: Writing Your Life Story Class

For PALS living in the Portland Metro/Vancouver and Salem areas, The ALS Association Oregon and SW Washington Chapter is excited to continue to offer an opportunity for people living with ALS to participate in a “Writing Life Stories Class.” Judith Pulman, Literary Arts Coordinator at the Multnomah Arts Center in SW Portland, will facilitate a 4-week session focused on supporting a small group of attendees in documenting the stories of their lives. Each weekly 90 minute class will be held at the Multnomah Arts Center in Multnomah Village in SW Portland and will allow participants to come together in a safe space to express their stories through writing. Judith will begin with the basics of writing and engage class attendees to look into the narratives of their lives and to share these stories.

No experience necessary! Both novice writers as well as more seasoned bloggers and storytellers are welcome. By collaborating with our Chapter staff, including Assistive Technology Coordinator Shana Tognazinni, the class is designed to be accessible to PALS with varying communication and writing abilities through the use of speech generating devices and adaptive computer equipment, as well as the dictation support of caregivers in the room when needed. At the end of the class, participants will be able to have tangible versions of their stories to add to their blogs, compile in keepsake binders, or record on video.

As each person living with ALS well knows, there are many stories to tell about your journey with this disease ... and there are also powerful personal narratives, memories and beliefs that are not defined by ALS. All of this is part of your life story. Your voice is important and your story is a gift for your loved ones to cherish.

Next session to begin in early Fall. Registration in late summer required.

Contact Rachelle Preston at 800.681.9851 ext 110 or rachellepreston@alsa-or.org with questions or to sign up!
Ask Shana
Q&A about Augmentative Communication and Assistive Technology

Dear Shana-

My mother has ALS and we were told that we should get her some type of “doorbell” system so that she can notify me when she needs me. Do you know how much they are, where to find them… etc?

Thank you for asking this question! Wireless doorbells are simple tools but can be incredibly beneficial for families of people living with ALS (PALS). There are several options to choose from so I want to outline them in order to help you find the best fit for your family.

First, I have a question for you: How is your mother’s hand function? Is she able to push a typical doorbell button with her finger?

If she has no issues, then purchasing a wireless doorbell off the shelf would be an appropriate option. Places like Target, Fred Meyers, Home Depot, or even Amazon, carry basic wireless doorbells. Some models even come with two different buttons which can be super helpful, allowing one button to be placed in the bathroom, and the other button on a chair or walker, for example. Typically, these doorbells range from $20-40.

**Wireless doorbell with two push buttons**

If she has experienced some changes in hand function, or if you are uncertain if she can press the button consistently, then I would recommend purchasing a switch-activated wireless doorbell. Switch-activated doorbells function like normal wireless doorbells, but they have an added bonus. These doorbells are helpful because they have been adapted so that a person can ring the bell by activating a switch that plugs directly into the button. Typically, these doorbells range from $40-50 and are available for purchase online from assistive technology companies such as adaptivetechsolutions.com.

**Switch-adapted wireless doorbell**

Switches come in various access points, sizes, and sensitivities, and are purchased online separately. They vary from large buttons that a person can tap with their foot, to small buttons designed to press with a finger, and even to thin wires that are able to be triggered with a chin or cheek. There are many assistive technology companies that offer switches, such as ablenetinc.com, and adaptivetechsolutions.com.

**Various switches**

In general, when we are looking at switch appropriateness, we look at all mobility access options. Is your mother able to move her hands, feet, knees, chin, head, finger, or jaw? If so, there are usually switch options that could be placed so that she can then activate the switch. There are even switches that look like straws that can be activated with a sip or puff of air. Given the correct switch and placement, a person can use almost any motor movement available in order to activate a switch, which would then ring the doorbell and signal a caregiver.

I usually recommend to PALS who are considering the purchase of a switch to first work with a specialist in order to help them identify an appropriate type of switch and location for placement. For PALS living in our chapter, I am available to help with this process. PALS living outside of our chapter may benefit from working with a specialist, such as an Occupational Therapist or Speech Language Pathologist, in order to assess for appropriate switch placement given changing mobility access.

Please let me know if you have additional questions re: wireless doorbells and switches, or other AAC/AT concepts. I am always here to help and happy to share information or resources that might benefit your family.

Thanks,

Shana

shanatognazzini@alsa-or.org | 800.681.9851 ext 104
Skype: stognazziniALSA | Facebook: stognazziniALSA
Beach Wheelchair Available!

Do you enjoy visiting the beach but are having a hard time navigating that sandy shoreline? Well look no further, we have the solution for you!

We have a loaner manual Beach Wheelchair to use for your trip to the coast this summer. While energy conservation and accessibility remain a challenge, it is important to continue to look forward to fun times and to create positive and lasting memories with family and friends.

Our beach wheelchair is easily dismantled and assembled for convenient transportation and with the help of a caregiver/loved one, you can traverse the sand and get up close to the ocean waves.

How?
Call our Care Services team in advance to reserve the beach wheelchair- we only have one! Families must pick-up and drop-off the chair at our Chapter headquarters office in Portland, Oregon.

Children’s Resources

While we often discuss the impact of caring for a loved one with ALS, it is important to also remember the affects ALS can have on the children and grandchildren of our families. Parents often ask us if, how, and when they should tell their children of their ALS diagnosis. Grandparents wonder how their grandchildren visiting from afar might react to their progression. Our chapter has compiled written material to help guide you through these processes, as well as referrals to local child development experts and play therapists. Please contact us for support in having these tough conversations.

FIVE TIPS For Talking with Children About ALS

All families are unique and each has its own customs and patterns of communication. Yet, there are some basic principles that apply to families with children of all ages when talking about ALS.

1. Be truthful and honest. Children should be told that their parent has a serious illness called ALS. The illness should be described using language and information appropriate for the children’s ages.
2. Both younger and older children need to know that it is not a communicable disease.
3. They need to know that it is no one’s fault that there parent has contracted ALS. (Young children tend to blame themselves when someone close to them becomes ill or dies)
4. Children need to know that no matter what happens, they will continue to be cared for and, specifically, by whom.
5. They should be encouraged to ask any questions whenever they occur. Keeping open a free-flowing dialogue will help both children and parents deal constructively with their emotions.

For more information like this, find our Children’s Resources link after clicking on the Local Care Services page of our chapter website, at www.alsa-or.org.

Fall 2014 ALS Family Fun Day

This NEW program is designed to both help parents and grandparents learn how to best support their children, of all ages, through their family’s journey with ALS as well as to provide a day full of fun and bonding with other children experiencing ALS and their families. If you are interested in participating, please email careservices@alsa-or.org to ensure you get on the mailing list.

New program offered through the Dougy Center

For the first time ever, families living with a life limiting illness will be invited to bi-weekly, age appropriate support groups. We are thrilled to be collaborating with the Dougy Center on this new service to the community. Contact your Care Services team for more information.
The Weight is a Gift

My name is Amanda Seidel and I’ve been given the opportunity to help my father, Robert (Bob) Seidel in his battle with ALS. Dad’s symptoms started in 2011 as arm weakness then progressed to a limp and in 2012, he was diagnosed with PLS (Primary Lateral Sclerosis). After a second opinion, he was diagnosed with ALS in May 2013.

Dad has always been a positive and benevolent man, without a harsh word to say about anyone or always able to see the good in the situation. I believe the longer Dad maintains his positive attitude, the longer we could keep ALS from taking control and wreaking havoc. Therefore, after discussing with Dad, the family and his doctor, we decided on an unconventional plan to provide Dad only pertinent information required for his current “at the moment” treatment and status rather than details about the entire disease course. I told Dad that I was going to worry regardless so there was no sense in him worrying too. I would carry it for us both.

Assisting a parent with a disease such as this is quite different than I would imagine assisting a spouse would be. At the center of our relationship, he’s still my Dad yet our core roles are inherently challenged based on how ALS works and the physical and emotional changes occurring. I find myself at odds on occasion when balancing the words I need to say with the person I need to say them to, reminding my father to do his stretches or asking him personal questions; and I always try to be conscientious of how, whatever it is, will it affect him – coming from his daughter.

For as long as I can remember my Dad and I have always been close so this has been a unique and arduous experience. In some ways, our bond makes it easier. I’m able to read between the lines and identify when he’s not speaking up about something but in other ways I’m torn apart literally watching someone murder my father, one of my closest friends right in front of me and I can’t do anything.

I know it’s out of my control but the guilt I feel from not being able to stop this is still breathtaking at times. I liken ALS to a lingering tornado – it touches down wherever it wants, you are helpless to its reach and its path, it takes with it whomever it chooses and leaves behind unimaginable wreckage. The presence of ALS has been devastating and left no alternative but to change me and my life, I’ve made choices I never thought I’d make; spent countless hours researching and reading about neuromuscular diseases, treatments & studies and written letters to politicians asking for their assistance in fighting this war. But whenever I feel like it’s too heavy and that I want to put it down, I remind myself it isn’t near the weight of what my father is carrying. I remind myself this weight I bear is my part, it is my gift.

Every time we turn around, it seems as though ALS is taking something new away but as of today it’s been over 3 years since it all started and Dad’s symptoms remain in his arms and legs so he’s still able to walk with a wheeled walker. It is a challenge at times, but I try to remain grateful for and focused on today.

I cringe when I hear people talk about killing time; I’ve been granted a special opportunity to be shown the delicacy of time and developed a genuine appreciation for it. I just can’t imagine killing anything so precious and irreplaceable. We continue to make the most of our time; we were fortunate enough to be able to take Dad on the vacation he always wanted to take, we moved him to a house that is more accommodating, giving him more independence and we get him whatever equipment he needs to maintain that independence. It’s important to not get lost in the appointments, bills, falls, etc. and to insert time for something memorable, take pictures, write down family stories, plant something together, do anything you’ll never want to forget – the minutes fall away without hesitation and the time does not come back.

The support from Dr. Goslin and The ALS Association has been immeasurable and Dad continues to have family and friends surround him and encourage him; having people there to help him with the simple things is invaluable because ALS always reminds you that simple isn’t the same thing as easy.

Rather than waste any time being angry or fearful or thinking about what will eventually come, I try to use that energy to demonstrate my father’s inspiring ethic and perpetuate his influence. I am fortunate to have the relationship I have with my Dad and I know that even though they are challenging, there will come a day I wish I had these moments back. I don’t want to look back and regret that I wasn’t more involved or feel like I could have done something else to make his life better.

As long as we’re both here I will be Dad’s advocate, I will make sure his voice is heard, that those who can make changes in policy and take action toward finding a cure at least know the names of those afflicted by this illness. I will stand beside him while he fights and when the time comes for him to take a break – I will take the fight on for him.
National Advocacy Day in Washington D.C.

On May 7th, advocates of The ALS Association from across the nation descended on Capitol Hill in Washington D.C. to raise awareness about people living with ALS and to request continuing funding for research. A team of eight people from our Chapter visited the offices of Senators Merkley and Wyden, and Congress members Blumenauer, Herrera-Beutler, Bonamici, Schrader, Walden and DeFazio.

Our delegation met Senator Merkley over coffee to discuss our concerns. We were impressed by Congresswoman Bonamici who invited the delegation into her office, listened, asked questions of our people living with ALS, Rob and Ken, and family members and remembered every delegate’s name. We met with Legislative Aides to discuss continued funding for the ALS Registry, research at the Department of Defense, the MODERN Cures Act and Medicare changes affecting Speech Generating Devices. After the meeting at Senator Wyden’s office, one of his staff, Dr. Justin Smith, contacted our Public Policy office immediately and will be working with them to address the Medicare changes regarding Speech Generating Devices.

For the 75th anniversary of Lou Gehrig’s famous speech, each Chapter created baseball cards for people living with ALS (PALS). The front of the card contains a PALS photo, name, residence and diagnosis date. The back of the card contains a short message to their respective Representatives and statics on ALS. The baseball cards were a powerful educational tool that moved a few Legislative Aides to tears as they read the short messages.

Thank you to all our delegation members who agreed to travel to Washington D.C. in order to educate our Representatives about the challenges and opportunities facing people living with ALS. They include: PALS Rob Chadwick, PALS Ken Feldhaus and family: Tina, Rachel and Rebekah; Board Members Tom Holt and Dr. Lou Libby (also member of the National Board of Trustees for The ALS Association) and Mary Rebar, Care Services Coordinator for the Willamette Valley.

---

**ALS Advocate**

Rob Chadwick
Scotts Mills, OR
Diagnosed with ALS in 2006

**ALS Advocate**

Ken Feldhaus
Hillsboro, OR
Diagnosed with ALS in 2012

**Know the Statistics on ALS**

- 2.5 Years of life expectancy after diagnosis
- 2x - Likelihood of diagnosis for veterans
- Effective treatments or care

---

My name is Rob Chadwick and I was diagnosed with Lou Gehrig’s Disease (ALS) in 2006. I was diagnosed with ALS at age 36. I’m a husband and a father. My daughter remembers when I could run, wrestle, and play soccer with them — my son doesn’t.

My contact information: rob.chadwick@gmail.com
Phone: 503-673-6824

Please join me in the battle against ALS by visiting www(ALS).org/advocate.

My name is Ken Feldhaus and I was diagnosed with Lou Gehrig’s Disease (ALS) in 2012. Husband of Tina and father of two wonderful daughters, Rachel and Rebekah. They join me in the fight of my life and in ALS advocacy.

My contact information: kennkładew@yahoo.com
Phone: 503-454-0407

Please join me in the battle against ALS by visiting www(ALS).org/advocate.
RIDE
to Defeat ALS

Ride to Defeat ALS
Presented by Alpenrose Dairy

Are you ready for the Ride to Defeat ALS on July 12?

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

This year, participants and guests will be treated to the same amazing rest stops along the 25, 50 and 100 mile routes that showcase Oregon’s beautiful farmland. We’re excited to introduce our newest route option – the Metric Century! The three-mile Family Fun Ride is always a great option for both kids and parents as it winds through the streets of Mt. Angel with fun stops for games and snacks.

Upon returning to the Finish Line Celebration, dinner from Silverton’s own Wooden Nickel Catering will be waiting for you, as will beer from the local Seven Brides Brewing and wine from Seufert Winery. Relax to the tunes of our favorite Silverton band, the Jim and Alan Show, now back for their third year of entertainment for our guests.

Our 2013 Highest Fundraiser, Ken Feldhaus, had a few inspiring words to say about his involvement in the Ride: “I ride because I have ALS and can still be part of the solution. The event is a special day that brings a diverse group of people in support of a single cause. I have met so many inspirational people during the celebration after the ride. If you like a great ride, great food and incredible people, come join us!”

The cost is just $35 (adults) and $15 (17 & under) to register. Each participant (ages 11 & older) is required to raise at least $150 to support The ALS Association. The goal is to raise $125,000 to support local care services, national public policy efforts and international research initiatives. We have no doubt that we will meet and exceed our goal in 2014 – help us get there!

So much excitement awaits you at the Ride to Defeat ALS. Don’t miss out on the Ride of Someone Else’s Life. For more information or to register, visit www.OregonRideToDefeatALS.org or call Rebecca Pace at 800.681.9851 ext 106 or email ride@alsa-or.org.

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We are proud to announce that because of more than 300 guests, participants and volunteers, our 2014 Ski to Defeat ALS raised close to $154,000! Congratulations to our Top 10 Fundraising Teams:

- **Team Fredinator** - $65,236.27
- **Franklin Control Systems** - $14,601.00
- **T.E.A.M. Mike Lopez** - $7,069.00
- **Robs Friends and Family** - $4,866.00
- **Patty’s Angels** - $3,730.00
- **Debbie’s Downhill Racers** - $3,585.00
- **Jack’s Tracks** - $3,527.00
- **Team Dan Berry** - $2,610.00
- **Les Schwab Celebrates Movement** - $2,500.00
- **Team Kyte** - $2,440.00

Collectively, our 2014 event participants tracked over 2.5 million vertical feet!

**2014 Top Vertical Feet Team Traveling Trophy Winner:**
Team Fredinator - 724,309 vertical feet

**2014 Top Vertical Feet Men’s Traveling Trophy Winner:**
Dale Parshall, Schnee Vogeli Ski Club - 61,539 vertical feet

**2014 Top Vertical Feet Women’s Traveling Trophy Winner:**
It’s a TIE! Sonja Taylor and Jennifer Wilson, Patty’s Angels - 59,354 vertical feet

Many thanks to our sponsors, partners and underwriters.

Mark your calendars for our 2015 Ski to Defeat ALS on **Saturday, April 11, 2015 at Mt. Hood Meadows**. We look forward to seeing you on the slopes and continuing to defeat ALS.
**Thank you to our 2014 Year-Round Partners:** Alpenrose Dairy, Fred Meyer, Northwest Medical, JGP Wealth Management, Wells Fargo and Numotion

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**Fred Noble 1937-2014**

**Ski to Defeat ALS Honorary Chair**

It is with a heavy heart we acknowledge the passing of Fred Noble on May 1, 2014, local ski legend and three time honorary chair of Ski to Defeat ALS.

After being diagnosed with ALS, Fred chose to turn his last years into a mission to make a difference for the cause of ALS. His efforts as the honorary chair of the Ski to Defeat ALS helped the event bring in over $480,000 in support of The ALS Association’s mission to provide critical care services and fund top notch research efforts.

To accomplish this, Fred worked tirelessly to promote the Ski to Defeat ALS and to help other people facing the disease.

Jump first, ask questions later and know you are doing well for others. You could not help but love Fred for his enthusiasm and his determination.

In his remembrance, we will award “The Noble Spirit Award” at each Ski to Defeat ALS as a tribute to his dedication and zest for life.

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**Looking for Local Business Members! Help us defeat ALS!**

**What is the Corporate Effort?**

An exclusive group of local business members who reach out to their professional and personal contacts to each give and/or get $2,500 for a collective goal of $100,000. This effort supports our region-wide goal of raising over $650,000 and our nation-wide goal of raising over $25,000,000 in 2014 alone.

Collectively, this esteemed group of local business members makes a BIG difference, contributes to the overall success of the 2014 Walk to Defeat ALS® campaign and reminds the ALS community that they are not alone.

**This can be through one or all of the following ways:**

- Letter/Email-Writing Campaign
- Sponsorship recruitment
- Walk Team
- Personal Contribution

**How do we recognize this esteemed group of supporters?**

- Recognition on the Walk to Defeat ALS® website.
- Recognition on the chapter website during the months of August and September 2014.
- Exclusive plaque to those that meet or exceed the $2,500 suggested goal.

**What is the time commitment?**

Our staff here at The ALS Association Oregon and SW Washington Chapter is here to take the WORK out of the WALK. We promise that this effort can take as little as 3 hours over a 3 month period (August – October). It’s your endorsement and contacts that drive the success of this effort. Our staff has the templates and the time to reach out on your behalf and is happy to do so.

**Contact Aubrey McCauley, Development Director, today at 800.681.9851 ext 105 or AubreyMcCauley@alsa-or.org to learn more.**

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**Your Gift, Your Way**

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

**Wife and Mother Philanthropist**

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

**Please contact Lance Christian, Executive Director or Aubrey McCauley, Development Director for more information.**

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**Save The Date!**

**ALS Annual Dinner & Auction Gala!**

**March 14, 2015**

Portland Ballrooms
Oregon Convention Center
We are less than 3 months away from our Walk to Defeat ALS®! This September, thousands of people throughout our region will lace up their walking shoes together, joining the fight against ALS. With an overall goal of raising awareness in mind – we are also working toward reaching our fundraising goal of over $650,000. With involvement from you, your family, friends, and coworkers, we can get there!

Join us for one, two or all six of our Walk to Defeat ALS® events including Portland Metro, SW Washington, Willamette Valley, State Capitol, Central Oregon and Southern Oregon!

**Central Oregon Walk to Defeat ALS®**
Saturday, September 6
Riverbend Park, Bend, OR
Contact Rebecca Pace for more information.

**Southern Oregon Walk to Defeat ALS®**
Sunday, September 7
NEW LOCATION! Bear Creek Park, Medford, OR
Contact Rebecca Pace for more information.

**State Capitol Walk to Defeat ALS®**
Saturday, September 13
State Capitol Grounds, Salem, OR
Contact Julia Mayfield for more information.

**Willamette Valley Walk to Defeat ALS®**
Sunday, September 14
NEW LOCATION! Alton Baker Park, Eugene, OR
Contact Julia Mayfield for more information.

**SW Washington Walk to Defeat ALS®**
Saturday, September 20
Esther Short Park, Vancouver, WA
Contact Julia Mayfield for more information.

**Portland Metro Walk to Defeat ALS®**
Sunday, September 28
World Trade Center, Portland, OR
Contact Rebecca Pace for more information.

Rebecca can be reached at 800.681.9851 ext 106 or RebeccaPace@alsa-or.org.

Julia can be reached at 800.681.9851 ext 107 or JuliaMayfield@alsa-or.org.

**Get Your Official Walk Shirt!**
Remember, registered participants who raise $25 or more are eligible to receive the official 2014 Walk to Defeat ALS® shirt!

**How do you raise $25?**
Ask five friends to skip their coffee and donate $5 to your efforts. Ask 3 friends for just $10. The more people you include, the more people will know about the Walk to Defeat ALS® and why you believe in this important cause. Nervous about asking in person? Let us help you draft an email to send, or link with our Facebook app once you register. It’s easy – we promise.

Trust us, spread the word about the Walk and you’ll be walking in style in no time!*

**Walk in Honor. Walk in Memory. Walk to Defeat ALS.**

*Fundraising of $25 or more is per registered participant and must be reflected on the personal thermometer in order to be tracked. Have questions, contact us at walk@alsa-or.org.

**Many thanks to our 2014 Top Sponsors:**

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*Trust us, spread the word about the Walk and you’ll be walking in style in no time!*
New and Exciting This Year . . .

Our Extra Mile Club!

Join us in taking the extra step and pledge to RAISE $1000 AS AN INDIVIDUAL by August 29th! Extra Mile Club members will receive special benefits and recognition on Walk Day.

WHEN YOU JOIN THE EXTRA MILE CLUB, YOU WILL GET:

- Special Walk to Defeat ALS® note cards which you can use to thank your supporters
- An Extra Mile Club Gift
- “I Walked the Extra Mile” button and sign on Walk day
- Your name listed on an Extra Mile Club sign at the Walk Start/Finish area
- Your name listed on our Walk to Defeat ALS® website
- Your name listed in our Chapter’s Annual Report for the associated fiscal year

*To receive the Extra Mile Club benefits, your pledge of $1,000 or more as an individual must be fulfilled and all money turned in to The ALS Association’s chapter office no later than Friday, August 29th.

*In order to be eligible for the Extra Mile Club, Walkers must be registered online and select “yes” to be a part of the program during registration. If you missed this question, no worries! Contact your Walk Development Manager so she can get you enrolled in this awesome club.

Walk To Defeat ALS 2014 Kickoff Party

Bring your determination, your energy and your passion in support of the Walk to Defeat ALS®. More than just a few-mile trek, it’s an opportunity to bring hope to people living with ALS, to raise money for a cure, and to come together with your friends and family to fight for something you care about. The Walk to Defeat ALS® is The ALS Association’s largest annual event, which raises funds to sustain care services and support cutting-edge research by the world’s best and brightest scientists.

Join us to learn how YOU can MAKE A DIFFERENCE!

2014 Kickoff Party
Sunday, August 17, 2014
1:00 – 2:00 pm
Oaks Park • 7805 SE Oaks Park Way, Portland, Oregon
RSVP Monday, August 11th: walk@alsa-or.org or 800.681.9851 ext 106.

Join us for a short and exciting hour of Walk to Defeat ALS® info, prizes and more! You’ll get to meet other participants, learn some hot tips and tricks, and enjoy Oaks Park!

RSVP early! The first 20 team captains to register by phone or email will receive 2 complimentary ride wristbands to use after the kickoff.
**Study Finds That Exercise May Reduce Risk of ALS**

ALS Association-supported research published in the scientific journal *Annals of Neurology* indicates that exercise does not increase the risk for developing ALS and may be protective. The role of exercise and physical exertion in ALS has been controversial. Previous studies have produced conflicting results but have generally been small or confounded by other flaws. To overcome these problems, a team of European researchers, led by Ettore Beghi, M.D., in Milan, Italy, interviewed more than 650 people with ALS and more than 1,100 matched healthy controls to determine their history of work and leisure-related physical activity. They found that overall physical activity was associated with a 35 percent reduced risk of ALS, whether the activity was due to occupation or leisure activity. Those engaging in more strenuous activity were at lower risk. As uncovered in previous studies, a history of repeated head trauma was associated with an increased risk for ALS. “This important study adds further to our understanding of risk factors for ALS,” said Lucie Bruijn, Ph.D., M.B.A., Chief Scientist for The Association. “While the study was retrospective, rather than prospective, in design, the robust results provide confidence that exercise is not associated with an increased likelihood of developing ALS and may even offer some degree of protection. Further work will be needed to identify the reasons for these effects, which may offer us some new ideas for developing treatments.”

**Researchers Discover Cell-to-Cell Spread of Misfolded ALS Protein in Cell Model**

In a study published in the *Proceedings of the American Academy of Sciences*, researchers at the University of British Columbia in Vancouver, Canada have found a potential new mechanism for the spread of ALS disease pathology in cell models. The results may point to possible new therapeutic strategies. Mutations in the gene for superoxide dismutase 1 (SOD1) are a cause of about 20 percent of familial or inherited ALS. Misfolded mutant SOD1 protein is believed to contribute to the disease process in those carrying the mutation, yet the role of misfolded non-mutant protein in the disease is unclear. Researchers in this study, who were led by Neil Cashman, M.D., of the University of British Columbia, Vancouver, Canada, showed that both misfolded mutant protein and misfolded normal protein can be released by one cell and picked up by another cell. The uptake of misfolded protein can lead to misfolding of normal protein in the cell that takes it in, propagating the misfolding process from cell to cell. That cell-to-cell transmission could be reduced by antibodies against the SOD1 protein. “These results are intriguing and potentially important in understanding the ALS disease process,” said Lucie Bruijn, Ph.D., MBA, Chief Scientist for The Association. “If the spread from cell to cell seen in this cell model also occurs in people with ALS, it could help explain the progression of the disease after it begins and point to blocking that spread as a new and important treatment strategy, including for individuals with non-SOD1-related ALS. However, more work will need to be done to determine whether misfolded SOD1 does in fact move from cell to cell in humans and whether this process contributes to the pattern of disease progression we see. Answering these important questions takes on new urgency with the publication of this study.” One approach to therapy would be to treat with antibodies against misfolded proteins. Several groups have shown that this strategy has benefit in the SOD1 mouse model of ALS. Investigators Janice Robertson, Ph.D., of the University of Toronto, Toronto, Canada and Joan Coates, University of Missouri, Mo. are testing this approach in a canine model of the disease in an Association-funded study.

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**Recap: 2014 ALS Research Forum**

On May 2nd, 2014 over 100 people gathered in Portland for The ALS Association’s 2014 Research Forum. The Audience was eager to hear from presenters Kim Goslin, MD, Ph.D, ALS Research and Clinical Trials Update; Joe Beckman Ph.D. SOD1 and possible therapies for ALS; and David Morton Ph.D TDP-43, ALS and how fruit flies may lead to a treatment for ALS.

To see a sample from the day’s research presentations, please visit our chapter YouTube Channel at: [https://www.youtube.com/user/ALSAOregon](https://www.youtube.com/user/ALSAOregon)
Upcoming Volunteer Opportunities!

Summer is here! We are in full prep mode for our Ride and Walk. Find out how you can be a part of these exciting events:

**Ride to Defeat ALS®**
Saturday, July 12 – Mt. Angel Festhalle, Mt. Angel, OR

**Walk to Defeat ALS®**
Saturday, September 6 – Riverbend Park, Bend, OR  
Sunday, September 7 – Bear Creek Park, Medford, OR  
Saturday, September 13 – State Capitol Grounds, Salem, OR  
Sunday, September 14 – Alton Baker Park, Eugene, OR  
Saturday, September 20 – Esther Short Park, Vancouver, WA  
Sunday, September 28 – World Trade Center, Portland, OR

For more information contact Rebecca Pace, Development Manager, by phone at 800.681.9851 ext 106 or by email at volunteer@alsa-or.org.

Volunteer Spotlight:  
Julie Swearingen

From helping to form and shape the Central Oregon Walk to Defeat ALS, to office projects, to Gala auction procurement, to set-up and tear-down at events, there isn’t anything Julie Swearingen won’t do to help in this fight against ALS. She honors the memory of her amazing grandfather, Bob Anderson, by volunteering for The ALS Association. With every job Julie accomplishes assisting our Chapter staff, she puts her heart and her soul into it.

We couldn’t be more excited to highlight her for our Summer newsletter.

“I started volunteering in 2006 when I moved back from Reno, NV and the plans were already under way for a Central Oregon Walk to Defeat ALS®. It was great to realize we were going to bring information about ALS to Bend.

But when we first got my grandpa’s diagnosis in 1999, I felt like I had no information; I barely knew who Lou Gehrig was, let alone what ALS meant. While I was taking an Intro to Public Speaking class and we were tasked with an informative speech, I instantly knew I wanted to speak about ALS.

Those first two years of college were hard: I kept my cell phone with me at all times; I never knew when I might get a phone call to go to his house, and I was terrified every time the cell phone rang in class.

The first few years of the Central Oregon Walk were great. I loved having my whole family involved, and friends would come to help. As the walks grew bigger, and the volunteers and teams expanded, I’ll admit it’s been hard to let go of being as involved as I was in the first years. It’s like watching a baby grow up. Now, though, I enjoy seeing how many people participate, and yet hate it because it means ALS is not gone. Every year someone I knew from high school, a job, or just through another friend has been at the Walk because their life is affected by ALS.

When I moved to Portland in 2010, I formed my own “The Bob Squad” with two friends and walked it. The last two years, I’ve volunteered at everything I possibly could either with friends, or alone, because I realized something: I don’t want this to continue. If I could give a million dollars to research a cure, I would. But since that’s not possible, I give a great amount of my time. Each day, or year, that goes by without my grandpa, and with another person receiving this diagnosis, I know I cannot sit back and wait for someone else to make the change. This is the first thing I’ve felt so passionate about that I finally understand “be the change you want to see in the world.” And if that helps someone else to come volunteer, donate, or just learn about ALS, then I couldn’t ask for anything more.

This last year and a half, especially being a part of the Gala procurement team, have meant more to me than I can express. Making new friends through The ALS Association is wonderful and heartbreaking: we never know when someone might leave us.

Volunteering for the ALS association has made such a profound difference in my life. One I hope would make my grandpa incredibly proud.”

We are sure that Bob would have been extremely proud of Julie. We see her dedication grow with each opportunity, and she is an invaluable asset to our organization.

Thank you for everything you have done and continue to do, Julie!

Julie Swearingen and Bob Anderson
# MONTHLY SUPPORT GROUP SCHEDULE

<table>
<thead>
<tr>
<th>Region</th>
<th>Meeting Details</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SOUTHWEST WASHINGTON REGION</strong></td>
<td>4:00pm - 5:30 pm, 100 E. 33rd St., Vancouver, WA 98664</td>
<td>Rachelle Preston, MSW at 800.681.9851 ext 110.</td>
</tr>
<tr>
<td><strong>WEST|SOUTHEAST GROUP</strong></td>
<td>3:00pm - 4:30 pm, 4805 NE Glisan St, Portland, OR 97213</td>
<td>Lance Christian, LMSW at 800.681.9851 ext 101.</td>
</tr>
<tr>
<td><strong>NEW LOCATION</strong></td>
<td>2:00pm - 3:00 pm, 2825 E Barnett Rd, Medford, OR 97504</td>
<td>Mary Rebar at 541-990-1246.</td>
</tr>
<tr>
<td><strong>FAMILY CAREGIVERS GROUP</strong></td>
<td>1:00pm - 2:30pm, 2825 E Barnett Rd, Medford, OR 97504</td>
<td>Gail Gallaher at 541-292-8775.</td>
</tr>
<tr>
<td><strong>STATE CAPITAL REGION</strong></td>
<td>3:00pm - 4:30pm, 930 Oak Street E, Salem, OR 97301</td>
<td>Mary Rebar at 541-990-1246.</td>
</tr>
<tr>
<td><strong>WILLAMETTE VALLEY REGION</strong></td>
<td>3:00pm - 4:30 pm, 2580 Hilyard Street Eugene, OR</td>
<td>Mary Rebar at 541-990-1246.</td>
</tr>
<tr>
<td><strong>SOUTHERN OREGON REGION</strong></td>
<td>2:00pm - 3:30pm, 2825 E Barnett Rd, Medford, OR 97504</td>
<td>Mary Rebar at 541-990-1246.</td>
</tr>
<tr>
<td><strong>CENTRAL OREGON REGION</strong></td>
<td>11:30am - 12:30pm, 2500 NE Neff Road, Bend, OR</td>
<td>Betsy Paige, LMSW, at 541-977-7502.</td>
</tr>
</tbody>
</table>

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