Join us to find a cure.

Want help getting signed up? Have questions or comments? Contact Meagan, your Walk coordinator at 800-681-9851 or walk@alsa-or.org.

Join in the celebration of hope, love and the remarkable spirit of the ALS community.
BOARD OF DIRECTORS

President
Trina Bandelow
Northwest Medical

Vice President
Dr. Louis Libby
The Oregon Clinic, LLC

Treasurer
John Seibert
Jarrard, Seibert, Pollard & Co. LLC

Secretary
Alexis Halmy
Windermere Cronin & Caplan Realty Group Inc.

Angelene Adler
CARE Medical, Inc.

Mary Beth Baker
Fred Meyer

Matthew Bassist
Ashforth Pacific, Inc.

Dr. Kimberly Goslin
Medical Director,
Providence ALS Center

Joseph Gross
JGP Wealth Management Group
of Wells Fargo Advisors

April Hughes-Sanders
Wells Fargo – Oregon Region Marketing

Alfred Lee
Perfect Breathing

Doug McClure, PsyD
Private Practice

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

Rep. Tobias Read
Nike, Oregon State Representative for House District 27

Elisabeth Twist
Attorney at Law

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

We will continue the fight in their honor.

February 17, 2011 – June 1, 2011


(This list is based on what we have been told; please notify us of any omissions or errors.)

HOW TO REACH OUR CHAPTER

Chapter Headquarters
ph: 503-238-5559 or 1-800-681-9851
fax: 503-296-5590
e-mail: info@alsa-or.org
website: www.alsa-or.org

The ALS Association
Oregon and SW Washington Chapter
700 NE Multnomah St., Suite 870
Portland, OR 97232

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

Development Director
Aubrey McCauley
AubreyMcCauley@alsa-or.org

AT Services Coordinator
Bets Peters, MA, CCC-SLP
BetsPeters@alsa-or.org

Services Coordinator
Sarah Greenstein, MSW
SarahGreenstein@alsa-or.org

Events Coordinator
Meagan Lancaster
MeaganLancaster@alsa-or.org

Bookkeeper and Office Manager
Caryn Porter
CarynPorter@alsa-or.org

Join us in welcoming our newest staff member!
Sarah Greenstein, MSW, Services Coordinator

Sarah brings a compassionate, strengths-based approach and over ten years of social work experience to her new position with The ALS Association. Since receiving her Masters degree in Social Welfare, Sarah has dedicated her professional energy to working with non-profit organizations to provide educational, community resource, and counseling services to youth and their families. In her previous positions as Clinical Social Worker and Program Coordinator, Sarah developed and implemented innovative new programs, facilitated support groups, and fostered community partnerships to empower individuals and families both in Southern California and Portland. During her graduate training at UCLA, Sarah had the opportunity to work in diverse community mental health settings including an outpatient day-rehabilitation center facilitating support groups for chronically mentally ill adults as well a professional consulting group providing academic and social support to students and professional development coaching to school staff. She is humbled and honored to begin working with individuals and families impacted by ALS and she is committed to supporting the highest quality of life at every stage of the process by building meaningful and compassionate relationships and empowering families by connecting them to necessary resources and supports.

Sarah and her husband Brad moved to Portland five years ago and are still in awe of the beauty and greenery of the Pacific Northwest. Watching their young daughters wake up to the world has allowed Sarah to explore Portland’s parks, gardens, and natural attractions through the joyful eyes of children. Sarah is excited to be planting her second vegetable garden this year, is active in Portland’s anti-genocide community, and enjoys walking, being outdoors, music, and laughing with her family.
My name is Fred Noble AKA “The Fredinator”.

After nine months of testing and getting 2nd-3rd-and 4th opinions, the diagnosis of ALS came in. All that time, I was hoping for a curable brain tumor. First time I ever went to the doctors wishing that.

I had essentially used up all my nine lives and faced certain death on numerous occasions - a helicopter crash in Canada, sinking an armored personnel carrier in Germany, an earthquake while working at the top of a 400 foot tower in Seattle, ducking a small airplane lost in an Orcas Island fog while setting the last section of a 180 foot tower (the plane came close enough to read BF Goodrich on the landing gear), lightning strikes, wind storms, hail storms, getting washed out to sea in Chile while windsurfing, hitting and dodging icebergs in Alaska.

There is more, but space does not allow me to list everything. To put it into a time span of my 74 years, this was like 5 years worth. The penultimate was my paragliding accident in Brazil. This was for sure the end but somehow after years of rehabilitation, I lived to tell this story.

I lived on the edge daily and I always thought I would die a violent death, doing things I enjoyed. Kind of a dumb attitude considering everyone would say I died doing what I enjoyed. I never wanted to die that way and did everything in my power to get to the edge and always come back.

Through this disease, I have learned a lot about myself and I’ve learned my friends know more about me than I do.

I look at this diagnosis as a serendipitous occasion - I get to say goodbye to my family and friends and perhaps leave a legacy by helping The ALS Association find a cure for others.

We are talking about writing a book. I wanted to call it “Thursdays with the Fredinator”. My apologies to “Tuesdays with Morrie” but perhaps a more appropriate title suggested by writer Phil Favorite is “The Noble Adventure”…coming soon to a book store near you.

Feel free to visit my new website and blog – we are in this fight together. www.frednobleadventure.com

I do not look at this as courageous or heroic but simply my survival DNA.

ALS is the new edge and it is likely there is no coming back. But, in the meantime, there is a lot to accomplish - preparing for my family (4 wonderful children), savoring every moment we have together and living life like its business as usual. They say “life is short “but if you jam as much as you can into it, it’s enough.

“Fredinator” did not come into being until I was diagnosed with ALS. It was my way of dealing with yet another challenge in my long and storied life.

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

It is constantly being updated with information on events as well as current care services.

Central Oregon
Regional Services Coordinator
Kathleen Ronning
ph: 541-977-7502
date: KathleenRonning@alsa-or.org
The ALS Association
P.O. Box 1855
Bend, Oregon 97709-9998

Southern Oregon & Eugene
Regional Services Coordinator
Gail Gallaher, M.Ed.
ph: 541-292-8775
date: GailGallaher@alsa-or.org
The ALS Association
2305 Ashland Street, Ste C, Box 458
Ashland, OR 97520

Thank you to our 2011 Year-Round Partners: CARE Medical, Northwest Medical & Fred Meyer
NW Oregon/SW Washington Update

Here at the chapter headquarters we are thrilled to welcome Sarah Greenstein, MSW to our Portland services staff. Lance Christian and Sarah have been busy orienting Sarah to the services provided by The ALS Association and connecting Sarah with families living with ALS so that she can learn firsthand the resources and skills it takes to live with ALS.

Lance has conducted home visits with 19 families newly diagnosed with ALS this spring. In the last 3 months, we have led 12 ALS support groups from Salem to Vancouver. Around 140 people have attended groups with topics that ranged from “ALS and Accessible Transportation” to “An ALS Research Update” with Joe Beckman Ph.D from Oregon State University. Dr. Beckman is the head of the Environmental Health Sciences Center at OSU and focuses his research on ALS and the SOD1 protein. We are grateful that he took time and drove up from Corvallis to give our Portland group an update on his work and the current state of ALS research.

It has been a busy spring for Betts Peters, our Assistive Technology Services Coordinator. In March, she traveled to the CSUN Technology and Persons with Disabilities Conference in San Diego, along with Karen Smith from the Providence ALS Center. They attended classes on a variety of assistive technology topics, including iPad apps, computer access, eBook readers, and eye-controlled communication devices. The conference was also an excellent opportunity to meet with vendors and get some hands-on experience with all of the latest innovations in assistive technology.

In May, Betts was part of the Oregon and SW Washington Chapter’s delegation to The ALS Association’s National Advocacy Day in Washington, D.C. The group, which included a family living with ALS, spent a full day at Capitol Hill, meeting with senators and representatives from our area and asking them to support continued funding for ALS research and the ALS Registry. The Advocacy events also included a full-day conference with sessions on promising new treatments and tips for meeting with our congressional delegation, as well as a candlelight vigil. It was a wonderful and empowering experience.

Betts also traveled to Medford in May to teach a seminar for speech-language pathologists in Southern Oregon. The SLPs in attendance received up-to-date information on both insurance-funded and “do-it-yourself” communication devices, as well as software and accessories that can be useful for PALS and others with speech and mobility impairments. Betts hopes to continue to teach these seminars around the state, to help ensure that PALS are able to access augmentative communication services in their local community.

Central Oregon Update

Spring in Central Oregon saw another clinic held at The Center with help from Dr. Vivian Ugalde and other clinic staff. Our Chapter Director, Lance Christian, joined us for this clinic session. Three additional clinics are planned for the rest of this year.

We are proud to be collaborating and working with JoAnne Bernt, PT, who has received the Oregon Physical Therapy Association’s Mercedes Weiss Service Award. The award is given each year to a therapist who has “made significant contributions in the areas of clinical practice, education, administration, research or practice management.” JoAnne has been a physical therapist at St. Charles for 22 years and is a true champion of people with ALS here. Congratulations JoAnne!

Kathleen Ronning, Central Oregon Services Coordinator, continues to meet with families, connect them with the loan closet and help with local resources. She attended the Senior Care Network presentation in March on Palliative Care. Dr. Lewis and Dr. Mavity, both Palliative Care doctors, presented. Dr. Lewis is part of the ALS clinic team.

During our March support group meeting, Sandra Charbonneau, a volunteer with Senior Health Insurance Benefits, provided information on Medicare changes that occurred as of January 2011. Barbara Zemke, a Social Worker with St. Charles Rehabilitation Outpatient clinic, joined us for our April meeting. Barbara is also the social worker for the ALS clinic team. We will be hearing about the Walk to Defeat ALS® and it’s exciting opportunities from Meagan Lancaster, our Events Coordinator, at our June meeting.

Two fundraising events were held in May and many friends and families ate dinner out for ALS at Pastini and Pappy’s Pizzeria. The annual May ALS Awareness event was held at the High Desert Museum on Saturday May 28th. We were delighted to welcome the Solomonson family (John, Georgia and Eric) from Damascus, Oregon to the snowy part of the State for our gathering. It snowed and hailed outside as we had our refreshments and remembered our loved ones and honored those with us living with ALS. Attendees visited the exhibits at the museum following the event.

Southern Oregon/Eugene Update

Regional Services Coordinator Gail Gallaher continues to support PALS and their families who are navigating the challenges of living with ALS. Outreach to the medical community, including home care and hospice providers, remains a top priority. Support groups in Eugene and Medford are well attended by PALS, their caregivers, and our long time friends.

continued on the next page
Speech Generating Devices Now Available through Oregon’s Telecommunication Devices Access Program

Communication is often difficult for people with ALS. They may experience speech changes, or mobility impairments that prevent them from answering or dialing a phone. Fortunately, there is a wide variety of assistive technology that can help with both face-to-face and telephone communication, allowing PALS to share their thoughts, feelings, and needs with family, friends and caregivers. In Oregon, one government program is working to put this technology in the hands of the people who need it.

The Telecommunication Devices Access Program (TDAP) provides adaptive telephone equipment to people who are unable use a regular telephone because of a disability. The equipment is loaned at no charge, and with no income restrictions, so it is available to any Oregon resident with a qualifying disability. Many people with ALS have taken advantage of this program. PALS with mobility impairments may benefit from a remote-controlled speakerphone, which allows them to answer and place calls with the click of a single button. Those with speech impairments and good hand function can use a TTY device to make calls by typing messages to a relay operator. PALS with reduced volume can try a voice-amplifying phone to help others hear them better over the telephone.

In February, TDAP announced the debut of their new Speech Generating Device Program. Speech generating devices are electronic communication devices that allow the user to enter a message and have it spoken in a computer-generated voice. Such devices can be used for face-to-face communication as well as telephone conversations. Those with impaired hand and arm function can use an alternative access method such as head control or eye control, allowing them to continue to communicate independently even when they cannot type on a traditional keyboard.

The majority of people with ALS who need a speech generating device are able to obtain one through insurance. However, some PALS may be faced with an insurance plan that does not cover these devices, or may have a high co-pay that they cannot afford. In cases such as these, the TDAP speech generating device program can be an invaluable resource.

Oregon is one of the first states in the nation to offer speech generating devices, thanks in large part to the work of Colin Portnuff, a PALS. As part of the TDAP Advisory Committee, he advocated tirelessly for the inclusion of speech generating devices in the program. (Some of you may also recognize Colin’s name from his booklet “So They’re Telling You to Get a Feeding Tube.”) Melanie Fried-Oken from OHSU and Chris Gibbons, the previous Assistive Technology Services Coordinator for The ALS Association (now also at OHSU), were also instrumental in the development of the TDAP SGD Program. Because of their efforts, PALS and other Oregonians with disabilities now have access to the technology they need for communication, regardless of their insurance or financial situations. The successful implementation of the TDAP speech generating device program is a great example of how PALS, their families, and our wonderful ALS community can make a difference in people’s lives.

For more information about the telephone equipment and speech generating devices available through TDAP, please contact our Assistive Technology Services Coordinator, Betts Peters, at 800-681-9851.

Statewide Services continued from page 4

In May, a seminar on speech generation technologies was presented in Medford by our own Betts Peters, SLP. The fifteen local speech therapists in attendance appreciate the dedication of our chapter to provide updated information and practices. We thank Providence Medford Medical Center for their support with our seminar.

A special nod goes to Michael, Tricia and Nathan Lytton of Eugene for their success in raising awareness about ALS. Michael was diagnosed with ALS in the fall of 2010. An avid runner, Michael, age 47, has run six marathons and twenty half-marathons. He and his wife and son chose to run in the Eugene half-marathon sporting tee shirts bearing the slogan, “ALS Bites.” Michael said he knew the other runners would see the slogan and become more aware of ALS. “Though I am normally a quiet fellow, I feel I need to help - and this is a way I can.” He and his family were interviewed by a local TV station prior to the run and shared their positive approach to living with ALS. Weeks later, Michael and Tricia honored our chapter by being our delegates at ALS Advocacy Day in Washington, DC. The Lytton family has our deep gratitude and admiration for their generous efforts.

The Grants Pass Daily Courier published a moving article in June about local families living with ALS. Kitty Quinn was diagnosed with ALS in March, 2009. Her husband Bob Quinn and daughter Tami Hollenbeck shared Kitty’s care until her passing this May. Both stressed the importance of teamwork in caregiving and the value of The ALS Association in offering equipment, information and support. They also received essential support from local families of PALS who recommended experienced caregivers. In Grants Pass there is a community of ALS volunteers, families and professionals who share the journey of living well with ALS.
An abundance of LOVE and SUPPORT was in the room at our Annual Gala on Saturday April 9th at the Hilton Portland and Executive Tower in Downtown Portland, Oregon.

People living with ALS and their families across Oregon and SW Washington have HOPE today because 525 generous supporters made this year’s gala a REMARKABLE SUCCESS.

Their participation in the evening and their dedication to the fight against ALS funded an outstanding $342,000 to provide free services to local families living with ALS as well as funding cutting edge research to find a treatment and a cure.

The success of this amazing evening is extraordinary! We are deeply grateful to the anonymous donors who offered matching opportunities during the evening. Many thanks to our supporter, Buck Makinson, of Bend, Oregon, for donating his time and photography services! And many thanks to Lindsay Gray of Lake Oswego, Oregon, who spoke in honor of and for her father, Arne Gray, who is living with ALS.

For a link to our photos or a link to the YouTube page, please contact us at gala@alsa-or.org and we will be sure to point you in the right direction.

Thank you Margie Boulé for your time and efforts in being the Mistress of Ceremony! You are a gem! And many THANKS to the 75+ volunteers that made this event possible.

This event like our Walk to Defeat ALS® gives families and caregivers FREE access to the tools, equipment, and resources they need to take control of their lives.

A BIG THANK YOU to our SPONSORS and SUPPORTERS! All money raised at the gala went directly to our services and programs thanks to those listed below!

And of course, many thanks to all of our donors to the Restaurant Frenzy, Desert Frenzy, Live Auction and Silent Auction opportunities of the evening — they made it easy to have so much fun!

TWO NEW CHAPTER EVENTS in 2012!

**Ski to Defeat ALS**
April 14, 2012
Mt. Hood Meadows

**What is the Ski to Defeat ALS?**
Ski to Defeat ALS is a team and individual skiing and snowboarding event hosted at Mt. Hood Meadows on Saturday, April 14, 2012. Participants engage in competition with each other on most dollars raised as well as most vertical feet skied or ridden. Fantastic prizes for the winners.

**Event Honorary Chair:**
Fred Noble, CMH Heli-Skiing & Summer Adventures

Fred has been with CMH as their original North American Representative for 38 years. Skiing has been his passion since the age of 17. Fred has traveled to and explored 81 countries; he has skied millions of vertical feet and has taken on a new and final chapter in his courageous and vivacious life. On December 12, 2010, Fred Noble was diagnosed with ALS. He is embracing this new journey and invites you to join him in building awareness about ALS and raising funds for The ALS Association.

**Ride to Defeat ALS**
July 2012
Mt Angel, Oregon

**What is the Ride to Defeat ALS?**
The Ride to Defeat ALS is a non-competitive cycling event that makes a big difference in the fight against ALS. Cyclists take up the challenge to ride 25, 50 or 100 miles to raise awareness and funds for services, advocacy and research. Starting and finishing in Mt. Angel, Oregon, the Ride to Defeat ALS is a fun and hope-filled event that has something for everyone. Avid cyclists can challenge themselves, while families can ride and have fun at the kick-off and finish line celebrations. Whether a cyclist is riding and raising pledges as an individual, or forms a family or corporate team, everyone can take satisfaction that they have made a difference in the battle against Lou Gehrig’s Disease.

**To learn more about how you can be a part of this event, please email ride@alsa-or.org.**
Michael and Tricia Lytton represent our chapter at The ALS Association’s Public Policy Conference in Washington D.C.

Each year, our local chapter of The ALS Association is able to sponsor a person living with ALS and their caregiver to attend our National Public Policy Conference in Washington, D.C. And each year, there is a remarkable family that accepts the challenge. This year, Michael and Tricia Lytton stepped up to the plate to advocate for people with ALS and their families in Oregon and SW Washington.

Residents of Eugene, Oregon, Michael and Tricia joined together with our chapter’s Public Policy Chair, Carolyn Anderson of Bend, Oregon and chapter staff Betts Peters and Meagan Lancaster. The team spent a full day in congressional meetings, sharing their ALS stories and lobbying for continued support.

This year, the team had three direct asks for our local leaders. First on the docket was for congress to appropriate $10 million to continue the National ALS Registry at the Centers for Disease Control and Prevention. Also on the list was to ask for $15 million to continue the ALS Research Program at the Department of Defense. Lastly, the team was looking for a co-sponsor for the MODERNN Cures Act – a program that would accelerate the search for a treatment for ALS and other diseases by removing barriers that limit medical innovation.

The local delegation was able to meet face-to-face with office staff, as well with Congressmen David Wu, Greg Walden and had a surprise visit with Senator Ron Wyden. Each of the eight appointments the team had were met with care, empathy and support as our local voices were heard and our stories were told.

Michael says, “For me, ALS Advocacy day was at times grim, at times electric - but in the end, a deepening experience. Grim because of the hint of desperation in our voices, because of the shades of other PALs who walked these paths before us. Electric, because of unexpected smiles and hope that jumped like sparks as our message was heard. And deepening because there was so much caring here; not just between advocates, but with our representatives and senators as well.”

Thank you to Michael, Tricia and Carolyn for dedicating time to advocate for ALS support. To become an advocate, please visit our website at www.alsa-or.org and look for the Public Policy links. You may also contact us at info@alsa-or.org to learn more.

The National ALS Registry is OPEN! Enrollment Underway!

As of October 19, 2010, every person living with ALS in the United States can self-enroll in the National ALS Registry!

The National ALS Registry may be the single largest ALS research project ever created and is designed to identify ALS cases from throughout the entire United States. Most important, the Registry is collecting critical information about the disease that will improve care for people with ALS and help us learn what causes the disease, how it can be treated and even prevented.

The ALS Association led the fight to establish the National ALS Registry, working with Congress to enact the ALS Registry Act and secure federal funding to design, build and implement the National ALS Registry at the Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry (CDC/ATSDR).

We are now pleased to provide the ALS community with the tools and resources available on our website to help people with ALS enroll in the Registry and to assist the ALS community in sharing news about the Registry.

Please visit http://www.alsa.org/policy/registry.cfm today to learn more or please contact Lance Christian, Executive Director and Social Worker at 800-681-9851 or LanceChristian@alsa-or.org.

State Advocacy Makes a Difference.

On May 16th, 2011 people with ALS and their families gathered at the State Capital in Salem, Oregon to raise awareness of ALS. With advocates present from across the state, we met with individual state legislators and members of the Governor’s budget staff to discuss ALS and the impact cuts in the Department of Human Services budget will have for vulnerable people living with ALS. Cuts to the Oregon Health Plan, and to the State In-Home-Care Program may reduce the amount of supports available to many low income people with ALS. We urged the legislature and the governor to continue to support and strengthen these important programs that help low income people with ALS access healthcare and long-term care supports.

Our own board member, Rep. Tobias Read (D) Beaverton introduced members of our delegation, Barb & John Deeming and Lance Christian, on the floor of the House of Representatives.

We thank Carolyn Anderson, our Public Policy Chair, and all the people who attended our Advocacy and Awareness Day and those who stopped by to show their support.
Help us raise $500,000+ to support local services!

Bend
Saturday, September 10th
Riverbend Park

Medford
Sunday, September 11th
Bear Creek Park

Salem
Saturday, September 17th
Riverfront Park

Eugene
Sunday, September 18th
Alton Baker Park

Vancouver
Saturday, September 24th
Esther Short Park

Portland
Sunday, September 25th
World Trade Center

Have you ever considered volunteering at one of The ALS Association's events?

We have several opportunities throughout the year that have a need for extra support. If you are interested in learning more, please email us at volunteer@alsa-or.org.

We are currently looking for people to become part of the Walk to Defeat ALS®. If you would like to be part of the planning process, let us know! Opportunities won’t take up a lot of your time, and they surely will make a huge impact!
Fundraising: It’s not all about just asking for money. It’s about having FUN!

Sometimes asking for a donation can be scary, even if it’s for a cause you really care about. Why not try putting the FUN in fundraising with these ideas!

**Throw a Party!**  Ask for $10 at the door, and try to get food donated from a local grocery store.

**Use Social Networking Sites!**  Post your story on Facebook. You can link people directly to your Walk Page. Check out our new Boundless Fundraising tool! It’s great!

**Create a team flyer.** Include pictures to hand out at work, church, games, or parties!

**Dine Out!**  Talk with a local restaurant about hosting a benefit night. This is a win-win because it will draw new customers to a restaurant and will benefit your Walk Team’s fundraising efforts, too!

**Shannon’s Angels do more than Walk the Walk**

“We may not be the biggest team, but we are working hard for each dollar we raise! Together, we can make a difference!”

This is a quote from Kelly Briseno, team captain of Shannon’s Angels. Last year was the first year that the team was part of the Walk to Defeat ALS®, and they brought in an amazing $3,500. The team formed in memory of Kelly’s brother, Shannon. Well, this year the Angels are going even bigger.

Kelly's mind never stops thinking Walk, and the events that she’s planned for the team this year are a testament to that. She hosted a birthday party for a relative and made it also a Walk team fundraiser. She and the team held a garage sale. They’re currently planning a benefit at a local bar, complete with a silent auction. She made custom wristbands, in their team color and with their team name, and sells them as a fundraiser for her Walk team at local businesses. Kelly and her team do more than think outside of the box – in terms of fundraising and building their team, they’re living outside of it.

It’s easy to be passionate about ALS, and it’s inspiring to watch Kelly as her heart drives her to take action. “I always tell everyone I meet about ALS…this is not a seasonal thing for me. This monster is always on my mind and I will continue to raise awareness and dollars until a cure is found,” says Kelly.

She created a Facebook fan page for her Walk team, where she sends weekly updates to the rest of the Angels. And if you read the wall of the Facebook group, Kelly’s team members are as inspired and as active as she is. Family and friends post memories of Shannon on the wall and encourage each other as they work toward their $5,000 goal. And what they’re doing is working. With more events and opportunities in the works, this team is already 75 percent to their team goal.

We can’t wait to see them not only blow their goal out of the water, but we are sure it will be by a lot!

**Kelly, you and your team are making a difference!**

Volunteer Spotlight: The Anderson Sisters

In our eyes, the Anderson sisters are dynamos. To put it candidly, our local chapter of The ALS Association wouldn’t be the same without Carolyn, Joan, Barb and Ellen. It was six years ago that they approached chapter decision makers about bringing The ALS Association’s national, signature event – The Walk to Defeat ALS® to Central Oregon. And while talking about it would be one thing, they took on everything from event planning to day-of support and ran with it. They help find sponsors, recruit event volunteers and more. They really are Walk-Stars!

And thank goodness they had the idea – Last year, the Central Oregon Walk brought in over $50,000 to support services in the Bend area and surrounding communities. After losing their dad, Bob, they remain a pillar of support to patients and families in the area.

Carolyn also volunteers her time as the chapter’s Public Policy Chair—coordinating and organizing state and national public policy appointments.

This effort takes a lot of time, between organizing initial meetings and necessary follow-up. Joan helps our local chapter immensely with securing prime on-air play for our Walk to Defeat ALS® public service announcements – an effort that really raises both awareness and participation in the Walk!

And even though Ellen lives in Idaho, she supports as much as possible and even travels to Bend for the Walk when she can.

Barb, Carolyn, Joan and Ellen – Thank you for your continued support. We can’t say it enough, but we appreciate you!
I want to be part of the Walk to Defeat ALS®. What do I do? How do I do it?

Register! You can sign up as an individual or join or start a team today! It’s easy. We promise. Visit www.WalktoDefeatALS.org to get started. You’ll be glad you did.

Make it personal. Just log in to your online participant center by visiting the website above. You can add a photo or a video. You can share your ALS story. We’ve provided a starting page for you, but you can make it shine. Plus, we know that if you personalize your page, you will be a more successful fundraiser. People will learn your story and want to support you.

Start yourself off on the right foot! Make a donation to yourself. It might sound silly, but if someone sees that you are dedicated enough to give just $10, they will be too. And let’s be honest – even $10 donations can add up fast!

Start spreading the news. Send an email. Send a letter. Post the Walk on your Facebook page. Tell your story. Through your online participant center, we’ve crafted some pretty great emails for you to use. You can use them as is, but think about changing them up a bit. We’ve done most of the work for you, so sending emails to your contacts will be quick, easy, and sure to bring success!

Spread the news, again. Another thing we’ve learned? The average friend, family member or coworker needs to be asked three times before they will take action. So don’t feel like you’re bugging by sending a follow up email a couple of weeks later. It’s worth it and they’ll probably thank you for the reminder.

Get the party started! Do you want to know something that we love doing? It’s helping you and your team get excited about Walk Day. Think about hosting a family BBQ or party. We’d love to come and help you brainstorm a team theme, fundraising ideas, and more!

Let us help you. If there’s another thing that we like doing, it’s taking the work out of the Walk for you. Let us help you customize your pages and send emails. Can’t get your picture scanned to put on your site? Send it to us and we’ll do it for you! We can even draft up a letter for you. If you have a question, just give us a call. We want to help you.

We want the Walk to Defeat ALS® to be an empowering and amazing experience for you.

Sponsor Support!
Without regional and local support, both financial and in-kind, the Walk to Defeat ALS® wouldn’t be the event that it has grown to become. We’d like to thank our current Walk sponsors for their commitment to raising awareness about ALS and providing local and national support to patients and their families. If you have a chance to visit any of the business below, thank them for being part of the Walk to Defeat ALS®! If you want to join this list, let us know.

National Sponsors:__________________

Exclusive Volunteer Sponsor:__________________

Regional Sponsors:__________________

Portland, Oregon Local Sponsors:__________________

Columbia Sportswear
Campbell and Company
Vital Life Foundation
Organically Grown
Portland General Electric

Bend, Oregon Local Sponsors:__________________

OnPoint Community Credit Union
Eberhard Dairy
Western Communications – The Bend Bulletin

Eugene, Oregon Local Sponsors:__________________

OnPoint Community Credit Union
Hope. Love. Walk.
That’s really what it’s all about and this year, you can wear those words on Walk Day. Walk participants who raise $25 or more will receive an official Walk to Defeat ALS® t-shirt.

On the Mountain Again!
Two Bend skiers who haven’t been on the slopes since symptoms of ALS began got to take a couple runs down the mountain with the help of Oregon Adaptive Sports and their partnership with Mt. Bachelor. Both Glenn Asbury and Stephanie McLagan were able to once again experience being out in the mountain air and feeling the thrill of gravity as they rode down the ski slopes at Mt. Bachelor. Oregon Adaptive Sports is a non-profit based in Bend.

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.”

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

Visit our webpage at www.alsa-or.org to learn more about how to follow us online!
He hit .295 with 29 home runs and 114 RBIs that last year in 1938 — a season most baseball players could only dream about. They called him the “Iron Horse” because he was known for his durability. But even in 1938, he was feeling tired by mid-season. And for him, a season like that was considered mediocre.

The next year started off much worse. “I think there is something wrong with him,” one sports reporter wrote. “Physically, I mean. I have seen ballplayers ‘go’ overnight, but they were simply washed up as ballplayers. It’s something deeper in this case.”

The reporter was right. Seventy years earlier, a French doctor named Jean-Martin Charcot had described a strange disease called amyotrophic lateral sclerosis (ALS), and in the seven decades since, very little had been learned about it. It was only in 1939 that ALS burst onto the world consciousness when Lou Gehrig, one of the greatest baseball players who ever lived, announced he was suffering from the disease, retired and died just two years later.

ALS would evermore be known to most people as Lou Gehrig’s disease. Unfortunately, when World War II was just starting in Europe in 1939, they didn’t know much about it. Unfortunately, after another seven decades has passed, that’s still true.

Still No Cure
Doctors do not know for sure what causes ALS. They don’t know how to slow its progression. They certainly don’t know how to cure it. Researchers debate among themselves and trade theories in science literature. Dedicated doctors, nurses, therapists, aides and especially family members work to reduce suffering and treat symptoms, but the disease is debilitating, progressive and terminal.

In the middle of this quandary is Joe Beckman, an Oregon State University professor of biochemistry, holder of the Ava Helen Pauling Chair in the Linus Pauling Institute and director of the widely recognized OSU Environmental Health Sciences Center. Major research programs are under way, and Beckman has been laboring in them for 15 years. The goal is a therapy or cure for ALS. But this disease is not simple. If it were, very smart scientists would have figured it out a long time ago, and that hasn’t happened.

“This is complex, and it’s not certain yet where the right answer lies,” Beckman says.

The complexity, from one perspective, is about whether to restore zinc, remove copper or stabilize “superoxide dismutase” (an enzyme that protects cells from damage). If you think that sounds complicated, consider that Beckman has a stack of scientific studies on his desk about a foot thick, at risk of toppling to the floor, that address this and a lot of other issues.

But if the OSU researchers are right — and they think they are — then at least some research programs may be on the wrong track, and their efforts to stabilize a certain biological function are misguided. Instead of helping, these approaches may lead to the death of motor neurons and progression of the disease. As it progresses, ALS causes lost motor function, paralysis and usually death within a few years.

Beckman and nine other researchers last year published what they believe is an important study that summarizes more than a decade of findings and helps make the case for their theory.

The work was funded by the National Institutes of Health, the Amyotrophic Lateral Sclerosis Association, and other agencies. And it’s been facilitated by the sophisticated mass spectrometry facilities at OSU, which allow detailed questions to be asked at levels never before possible.

Copper May Be Key
Therapies that could remove copper atoms from superoxide dismutase (SOD), the OSU team believes, would allow it to die and be naturally eliminated. In the process, they could form the basis for a treatment for ALS. Researchers say this could stop the progression of the disease, while others in the science community continue to argue that copper is irrelevant.

“With the approach we’re using, we can already remove copper atoms in cell cultures and stop the death of motor neurons,” Beckman says. “We haven’t done this yet in animals, and some researchers who disagree with us point to certain experiments that they say show this won’t work. But I think this issue is more complex than many understand and those experiments are flawed.

“The devil is in the details,” he adds.

Complexity is a word that keeps coming up in discussions about ALS. That’s the sometimes painful process of science, which rarely yields simple findings and unchallenged facts. With ALS, some things are known. The disease results from the death of nerve cells in the brain and spinal cord. It’s less clear what starts that process,
Holding Out Hope (continued)

how it could be slowed or stopped, and there’s no known way to detect it before it begins.

Which brings us back to copper-zinc SOD, an antioxidant that helps rid cells of harmful molecules known as free radicals. A genetic mutation in the SOD gene leads to a zinc-deficient form of this compound, and some people with this mutation are far more likely to get ALS.

“In healthy people, superoxide dismutase compounds sort of partner together, fighting back-to-back to make each other stronger and help protect other cells,” Beckman says. “In ALS patients, for genetic or other reasons that are not clear, this process breaks down. Zinc-deficient SOD proteins begin to lose their shape and function, and the end result is dead motor neurons.”

Many researchers believe that stabilizing these mutant proteins would help prevent the progression of ALS. “Some neuropathologists look through a microscope at damage from ALS, and they see the tangled globs of misfolded proteins that are hallmarks of the disease,” Beckman says. “They find SOD associated with that, and think that’s the cause of ALS, and believe preventing that damage, preventing that unfolding, is the way to a therapy.”

Beckman’s findings are just the opposite. They suggest the SOD damage is just step in the process and an early one at that.

“We believe that keeping this dysfunctional superoxide dismutase around just makes things worse, creates a situation that is even more toxic to motor neurons and leads to the disease,” Beckman says. “Our studies indicate the best thing is to just let the zinc-deficient SOD go ahead and unfold, fall apart and be naturally eliminated.”

Scientists have found that removing copper atoms from this zinc-deficient SOD allows just that. The SOD is eliminated and does not create a toxic environment. In cell cultures, this has been shown to stop the death of motor neurons.

Therapies that would do this effectively don’t yet exist, but Beckman says they could. It would probably be a drug that helps remove the right amount of copper in cells in the right places, a metabolic balancing act that may be tricky but possible. “The real cure to defective superoxide dismutase is not to try to stabilize it; it’s to get rid of it. Removing copper is a way to do this, and we believe in that direction may lie a cure for ALS.”

Hope for Today

While this work goes on, 30,000 Americans have ALS at any given time, and Beckman provides what relief he can as he makes progress on the research front.

“Joe is a brilliant scientist, but he can also explain these very complicated topics in ways that others can understand,” says Lance Christian, executive director of the ALS Association of Oregon. “He regularly meets with our support groups to help explain the latest research findings. And he’s very patient, never rushed. Even though the science is so narrow and focused, Joe will answer every question, and he understands the larger issues of real people dealing with this disease.”

Beckman says that’s important, and he gets upset when he hears stories about people being told “nothing can be done.”

“There’s a lot we can do for people who are stricken with this horrible disease,” Beckman says. “We can’t cure it yet, but we can provide hope. And we can make sure that patients get all of the special help they may need to watch their nutrition, communicate, breathe, reduce their stress levels. That can improve both the quality and length of their life.”

ALS affects everything from swallowing to maintaining weight, breathing, and in some cases, cognition. Fatigue and depression are common. Most people die from respiratory failure or pneumonia within a few years of diagnosis.

“ALS is such a difficult disease that it not only can kill individuals but can destroy families, with the constant struggles and demands for 24-hour care,” Beckman says. “We have to do everything we can to help people until we can finally figure out exactly what is causing this disease.

“And when we do that, I really believe we can find a therapy for it, at least a way to slow or stop its progression. We’ll see the day when ALS is no longer a terminal illness.”
An ALS Promise: Honoring a hero.

When Steve Sall passed away from the effects of ALS in September 2010, the entire community lost a hero and every underdog lost a champion. Most importantly, Steve's family lost their beloved husband, father, brother and son. In his life, Steve was the first person to ask, “How can I help?” and “Did I make a Difference?” His philanthropy and human kindness ranged from tutoring math for Aloha High School students to serving on our chapter's Board of Directors and helping other people with ALS who had less means than himself. Those things only scratch the surface of the generous and kind person Steve was.

For Steve's wife, Teri, as she continues to move ahead in life, the frequent question she asks when facing any problem or situation is “What would Steve do?” The answer that most frequently comes back is “help make a difference.” Teri has stepped up in a “big way” to make a difference for other families living with ALS.

The ALS Association Oregon and SW Washington Chapter is pleased to announce that the Sall Family has established the “Steve Sall Promise Fund” with a generous $25,000 bequest from Steve's estate. This fund, with its interactive website and memorial, will act as a perpetual beacon of hope from Steve to his community and all people affected by ALS.

While Steve was living with ALS, he made a promise to make a difference. His Walk team collectively raised over $75,000 over 3 years of active participation while he was with us, and his friends and family rallied around our other chapter events as well.

With the establishment of the Steve Sall Promise Fund, we can say — a promise made, a promise kept.

The ALS Promise Fund

The ALS Promise Fund was created for all who know the heartache of this disease and who come together to contribute their stories, their memories, and make their ALS promise.

Your Promise Fund gives you the opportunity to create an enduring tribute to someone special. Share their unique story on the Promise Fund website in your own words and by contributing photos, video and creating a spoken remembrance—a recorded tribute—to your loved one.

You can create your own Promise Fund through a gift of $25,000 or more. This gift may be made over a period of up to five years.

The Promise Fund honors and celebrates people living with ALS and the individuals who provide care and support.

Make Your Promise Today. . . Help Create a Tomorrow Without ALS.

The ALS Promise Fund, for all who know the heartache of Lou Gehrig's Disease, the Promise Fund is an opportunity to join with family and friends and honor someone you love.

The ALS Association invites you to establish a permanent tribute at www.ALSpromise.org and celebrate someone special.

For more information call 800.681.9851

Contact Lance Christian at info@alsa-or.org
The Legacy Society of The ALS Association was established to recognize individuals who have included the Association in their long-term plans through a bequest, life-income gift, or other planned gift arrangement. Among the Oregon and SW Washington Chapter’s most valued supporters, members of The Legacy Society have determined that their legacy will be one of hope – hope that a cure for ALS will be found and that those living with ALS will be helped and supported during their lifetime with vital patient services.

On behalf of the 30,000 Americans living with ALS, it is our privilege to invite you to become a member of The Legacy Society, helping to ensure that ALS does not compromise the lives of future generations.

An Invitation to Join The Legacy Society
Members of The Legacy Society have expressed their commitment to The ALS Association, Oregon and SW Washington Chapter through a very special and important form of financial support. These donors have named ALS as the ultimate beneficiary of a planned gift. Such gifts might include a bequest and/or charitable income gifts such as gift annuities, remainder trusts, or gifts of life insurance.

If your estate plans include The ALS Association, please let us know by contacting Lance Christian, Executive Director, at LanceChristian@alsa-or.org or 800.681.9851.

We would like to thank you for your generosity by including you in The Legacy Society.

Membership Benefits
Your membership involves no dues, obligations, or solicitations, but it does allow us to thank you and recognize you for the plans you have made, and it may inspire generosity in others. Benefits of membership in The Legacy Society also include invitations to special events and seminars and a subscription to our newsletter. The most important benefit, however, you will receive from joining The Legacy Society is the satisfaction derived from making a lasting contribution to our organization’s long-term strength.

We are pleased to recognize the following local members of The Legacy Society:

- Mary Beth Baker
- Trina and Jeff Bandelow
- Lance Christian
- Leonard Davis
- Cynthia A. Greene
- Michael S. Lamont
- Lou and Jocelyn Libby
- Aubrey McCauley
- Fred Noble
- Steve and Teri Sall
- John and Barbara Seibert
- Nancy E. Shire
- Elisabeth Twist

We look forward to adding members in the future to this ever-growing list of committed individuals.

The ALS Association accepts donations of stock certificates, mutual fund shares, and other investment securities. Please contact Lance Christian, Executive Director, at 800-681-9851 or LanceChristian@alsa-or.org for more information.

Many thanks to the Community 101 students at Centennial High School! Through a program in partnership with the Oregon Community Foundation, our chapter was awarded with $1,000 in support of our Respite Care Program.

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:


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

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

Thank you to our 2011 Year-Round Partners: CARE Medical, Northwest Medical & Fred Meyer
THE VOICE
Bringing you the latest news on fighting Lou Gehrig’s Disease in Oregon and SW Washington.

SUPPORT GROUP SCHEDULE

Portland, Oregon
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 or Clare Cross RN at 503-963-3129
In Partnership with the Providence ALS Center. All people with ALS are welcome regardless of where they receive their care.

Portland Family Caregivers Group
3rd Thurs. of every month, 4:00pm – 5:30pm
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 or toll free at 800-681-9851

Medford, Oregon
3rd Tues. of every month, 2:00pm - 3:30pm
Medford Family Caregivers Group
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

Salem, Oregon
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 or toll free at 800-681-9851

Bend, 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: Kathleen Ronning at 541-977-7502

Eugene, Oregon
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

Vancouver, 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
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 or email info@alsa-or.org. This will help us save valuable resources in both printing and postage costs.

Want to request a topic for discussion or presentation at your next support group?
Contact Lance Christian at LanceChristian@alsa-or.org, 503-238-5559 or toll free at 800-681-9851