Raise awareness, raise dollars, raise hope.

Just ten years ago, there was no such thing as the Walk to Defeat ALS® in Oregon and SW Washington. Just ten years ago, people were being diagnosed with ALS, but they had nowhere to turn. Just ten years ago, hope was hard to come by.

Fast forward ten years to 2012. The ALS Association has a firmly-rooted chapter, serving all of Oregon and the six counties of Southwest Washington. At any given time, over 300 people living with ALS and their families are receiving information, care and hands-on support. And that hope? It’s taking over.

The ALS Association is expecting over 5,000 people to gather at Portland’s World Trade Center on Walk Day. Combining participation of all six walks throughout the region, more than 7,500 people will come together raising well over half a million dollars in the fight against ALS. Feeling alone is an easy thing to feel when receiving the ALS diagnosis. The power of the Walk to Defeat ALS® is being surrounded by people who know exactly what ALS is. No explanation is necessary. The only thing that exists is a community, an intimate one, made up of so many remarkable people who are all walking or rolling in the same shoes.

Will D. knows all too well the impact that ALS can have on a person, a family, and a community. Will was the primary caregiver for his friend and partner, Jeff, until Jeff lost his ALS battle in 2010.

“To lessen the burden of suffering for another is perhaps one of the most treasured qualities found in the human heart and mind. It is this living compassion that the ALS Association team offered us, and I honestly do not know what I would have done without them. I could have fallen to pieces from overwhelm when Jeff needed me the most. I am immeasurably grateful that I received guidance along the way.”

ALS isn’t something that’s talked about very often. And for something that is ironically diagnosed at the same rate as Multiple Sclerosis, there is never a large enough patient population at one time to advocate for more. But, what we know is there are a lot of people who care about those affected by ALS. By signing up for the Walk to Defeat ALS® and spreading the word, you will help find many more. With everyone doing their part, we will raise awareness. We will raise money and most importantly, we will raise hope.

“Raise awareness, raise dollars, raise hope.”
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 1, 2012 – June 11, 2012

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

Congratulations Kathleen!

It is with sadness and joy that we announce that Kathleen Ronning, our Regional Services Coordinator serving Central Oregon is retiring on June 30th, 2012. We are thrilled that she and her husband Bruce will be entering the adventure of retirement. But we will also miss Kathleen's commitment, advocacy, and common sense approach to serving families living with ALS.

Piloting the role in this newly created position for the last five years, Kathleen has been our pioneer. We can say without a doubt Kathleen's work has made a difference for families living with ALS in the Central Oregon community. From the establishment of our monthly support group, to partnering with St. Charles healthcare professionals to provide a monthly support group, to partnering with the board members, the people living with ALS who have allowed me into their lives and our amazing Bend ALS clinic team have all enriched my life beyond words. I thank you from my heart. I will miss these personal connections but will continue to stay connected to the mission.

The great news is that Betsy Paige will be jumping right in to take over the regional services position for the last five years, Kathleen has been our pioneer. We can say without a doubt Kathleen's work has made a difference for families living with ALS in the Central Oregon community. From the establishment of our monthly support group, to partnering with St. Charles healthcare professionals to establish a multi-disciplinary ALS clinic in Bend, Kathleen has worked diligently for the welfare of families living with ALS.

Kathleen, we thank you for your work and wish you well on your next adventure!

A Personal Message From Kathleen

My husband Bruce and I are retiring at the end of this month. I have been so blessed to have been able to serve as the Central Oregon Regional Services Coordinator for the past 5 years. I am grateful to all that have made this time meaningful, fun and personally rewarding in so many ways. The Chapter staff that I have worked with, the board members, the people living with ALS who have allowed me into their lives and our amazing Bend ALS clinic team have all enriched my life beyond words. I thank you from my heart. I will miss these personal connections but will continue to stay connected to the mission.

The great news is that Betsy Paige will be jumping right in to take over the regional services coordination. She is excited to get started and I am happy to be a continuing resource for her.

All my best,
Kathleen

Save the Dates for 2013

March 9, 2013 - Annual Dinner and Auction Gala
April 13, 2013 - Ski to Defeat ALS
July 13, 2013 - Ride to Defeat ALS
September 2013 - Walk to Defeat ALS

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

How to Reach Our Chapter

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

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PARTNERS
Thank you to our 2012 Year-Round Partners: Fred Meyer, Northwest Medical and Wells Fargo
Portland Metro / NW Oregon / SW Washington

The services staff in the chapter office has been busy providing direct services for people with ALS across the region. These services include direct counseling to families, guidance in accessing healthcare services and insurance and benefits counseling. Besides home visits to families living with ALS, our staff have worked at 15 ALS Multidisciplinary clinics at the Providence ALS Center and have facilitated 18 ALS support groups over the last 3 months. Our Medical Equipment loan closet has been very active and has provided dozens of families living with ALS the tools they need to be independent and to have a better quality of life. In these economic times, our loan closet has become even more important as we have become a crucial resource for people with ALS who have no health insurance.

Our partnership with The Providence ALS Center continues to be strong. We are thrilled to be working with Dr. Kimberly Goshin on a study looking at the impact of multidisciplinary care for people with ALS. This study involves 15 ALS clinics across the United States and is an effort to understand and show the efficiency and benefits of the multidisciplinary model of care for people with ALS. Families living with ALS certainly know the benefit of this model of care. We are happy to contribute some empirical data to support the efforts of clinics across the country.

Our new Assistive Technology Services Coordinator, Shana Tognazzini, has been busy introducing herself to the ALS community. She is already working with people living with ALS and families in their homes and at the Providence ALS Center. Shana is currently working on several projects planned for this summer, including taking inventory and re-organizing the Assistive Technology Loan Closet, and designing a new Augmentative and Assistive Technology Program brochure for our chapter. She looks forward to meeting many people in our community in the upcoming months, and plans on attending the Walk to Defeat ALS® in several cities later this fall.

Southern Oregon/Willamette Valley

The commitment to raise awareness about ALS continues to build throughout our area. People living with ALS willing to be followed in the media generously tell their stories, revealing both the challenges of living with ALS and the spirit to live well every day. Michael and Tricia Lyttun have become familiar to Eugene and Springfield TV viewers as they run and walk paths together, and discuss the course of Michael’s disease. Colton and Tiffany Allen of Talent have been interviewed by the Oregonian, Medford Mail Tribune and Ashland Daily Tidings. They also appeared on the public radio program, Jefferson Exchange where Colton, age 32, talked about following his passions and the crucial support of his family. Leatris McCoshum and her husband, Keith talked with the Grants Pass Daily Courier about Leatris’ recent diagnosis and the support of their faith community and family. Barbara Rorth and her husband, Harvey, now in their tenth year of living with ALS in Ashland, have appeared on Jefferson Exchange and KCMX talk radio where Barbara participated via email. Making each of these real stories available to the reading, listening, and watching public engages our communities to care about ALS. We salute the courage and generosity of the Lyttuns, Allens, McCoshums and Rorths!

Helping us in our media outreach efforts are volunteers Bill Weil and Grant Walker. Bill and Grant, who have personal ties to ALS, share their expertise in public relations. Both have committed time to meeting with Regional Services Coordinator, Gail Gallaher, offering networking connections and guidance. Gail has given speeches to Kiwanis and Rotary clubs and appears in print and radio interviews. She continues outreach to neurologists. Stepping up our visibility and making the ALS Association familiar to the community is a top priority.

Support groups in Medford and Eugene continue to offer the opportunity to people living with ALS to learn from each other and from speakers, such as Leslie Black, physical therapist and Eric Aramori, respiratory therapist. Community partners at the Medford Eagles Lodge provide a monthly lunch and emergency funds for out-of-pocket expenses. Under the continued from the next page

The ALS Association accepts donations of stock certificates, mutual fund shares, and other investment securities. Please contact our chapter for more information.

Regionwide Services continued from page 4

direction of Betty Johnson and Rae Earhart, funds have been received to help with van repairs, meals charges during hospital visits, computer repairs, and kids’ holiday gifts. Thanks, Betty and Rae! And, as always, we thank Garry Flaim of CARE Medical for managing our loan closer.

Central Oregon

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 the May clinic.

The ALS Clinic is sponsored by St. Charles Medical Center and meets every two months with a full multi-disciplinary team. We are grateful that the Central Oregon Community gets high quality local care. Our chapter recently helped the clinic with the purchase of a new respiratory pressure meter to be used during ALS Clinic. This tool will help the Respiratory Therapist and Pulmonologist have better data to support people with ALS in managing respiratory symptoms.

Spring Cleaning in the Summer

The time has come for some much needed “spring cleaning” for the Assistive Technology Loan Closet. Currently, the closet is looking a little bare and inventory shows that there is a lot of equipment out in the community… we need your help to help stock the closet!

If you have been loaned assistive technology equipment from The ALS Association and are no longer using it, this is a great way to give it back to the community. We can pick up the equipment and restock it for the next person who may need to borrow it.

Believe that you may have borrowed equipment, but can’t remember what you borrowed? That’s okay! Most equipment has been tracked with ID numbers and can be easily looked up to help you locate the separate pieces that you might still have at home. Remember, most items have a yellow or white ID sticker on them that includes our name and ID number.

Even if you have never received a loaned piece of equipment, you can still help! Often, there are old or unused pieces of equipment sitting around our homes that could be a great contribution to the Assistive Technology Loan Closet and could be beneficial to many people living with ALS.

We are thrilled to welcome Betty Paige, LMST to our team and thank Kathleen for her continued help with training and being a “retired resource!”

Kathleen Ronning, our regional service coordinator, continues to connect with newly diagnosed people and their families. Currently, our families come from Madras, Culver, Sunriver, Prineville, LaPine and Bend. Helping to serve these families through our medical equipment loan closet is, Ruth Little from NORCO Home Medical Equipment. We do appreciate their continued involvement as do those receiving their services. We could not support families in Central Oregon without their sponsorship and support. Thank you NORCO!

With Kathleen Ronning our veteran services coordinator retiring, we have been busy recruiting a new stellar person to try to replace Kathleen. We want to thank JoAnn Bernt, PT and Carolyn Anderson, community volunteer, for their help in our recruitment process.

We are thrilled to welcome Betty Paige, LMST to our team and thank Kathleen for her continued help with training and being a “retired resource!”

benefits the access and communication needs of many people living with ALS in Oregon and Southwest Washington. Please contact Shana Tognazzini, Assistive Technology Services Coordinator, for further information.

She is able to be reached by phone (503) 238-5559 extension 4, or by email at shanatognazzini@alsa-or.org. Or, of course, by social media… see below.

Facebook: www.facebook.com/stognazzinialsa
Twitter & Skype: stognazziniALSA

Thank you to our 2012 Year-Round Partners: Fred Meyer, Northwest Medical and Wells Fargo

A newsletter from The ALS Association Oregon and SW Washington Chapter

Thank you to our 2012 Year-Round Partners: Fred Meyer, Northwest Medical and Wells Fargo
Welcome Betsy!

Shana Tognazzini, MA
CCC-SLP is new to The ALS Association but not new to living with ALS. As a college student, Shana developed a passion for helping her father communicate with assistive devices during his own short battle with the disease. Since that time, Shana has earned her Master’s in Communication Disorders from the University of Oregon and is an ASHA-certified Speech-Language Pathologist with a specialization in Augmentative/Alternative Communication and Assistive Technology. She feels that her passion for helping others communicate is a gift that stemmed from her family’s experience with ALS.

Shana’s family moved to Central Oregon one year ago with her husband, and two young boys aged 2 and 6 after spending 3 years in Denver, Colorado. Betsy is happy to be returning to the Pacific Northwest which she considers home. Betsy aspires to attain balance between her work and time spent walking her dog on the trails, bike riding with her boys, listening to music, yoga and anything creative.

With gratitude to

People with ALS may need extensive durable medical equipment (DME) at some point during their illness. Our Durable Medical Equipment Loan Closet is generously hosted, free of charge, by our ‘Partner In Care’ - Care Medical & Rehabilitation Equipment.

Our inventory of equipment consists of over 500 items including manual and power wheelchairs, bath seats, patient lifts, and most recently, a beach wheelchair. Care Medical stores and maintains these items at their Corporate Headquarters in Portland, Oregon. Care Medical provides a dedicated customer service representative, Assistive Technology Professional, certified repair technicians, and delivery driver to assist people with ALS in obtaining the equipment that meets their specific healthcare needs. This partnership with Care Medical Equipment ensures our families receive free support while waiting for insurance coverage or when various DME products are not covered by their insurance plan. Through this generous partnership with Care Medical, people with ALS up and down the I-5 corridor have insurance Plan. Through this generous partnership with Care Medical, people with ALS have access to much needed durable medical equipment.

Betsy moved to Central Oregon one year ago with her husband, and two young boys aged 2 and 6 after spending 3 years in Denver, Colorado. Betsy has had the opportunity to work with people in an Adult Day Health setting facilitating various groups and activities including art, singing and spirituality and care coordination. Betsy worked as Medical Social Worker in Seattle and Harborview Medical Center assisting people with community resources, long term planning, advance directives and offering crisis support in the intensive care unit.

Welcome Shana!

Shana Tognazzini, MA
Wentworth Medical stores and maintains these items at their Corporate Headquarters in Portland, Oregon. Care Medical provides a dedicated customer service representative, Assistive Technology Professional, certified repair technicians, and delivery driver to assist people with ALS in obtaining the equipment that meets their specific healthcare needs. This partnership with Care Medical Equipment ensures our families receive free support while waiting for insurance coverage or when various DME products are not covered by their insurance plan. Through this generous partnership with Care Medical, people with ALS have access to much needed durable medical equipment.

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Welcome Betsy!

Betsy transitioned her role as a medical social worker from the hospital setting to working with people in their homes and long term care settings as a hospice social worker in Seattle, Washington, Boulder, Colorado and most recently in Prineville, Oregon. Within this role, Betsy regularly facilitated family meetings, care conferences, short term counseling, anticipatory grief support, end of life education, caregiver support, connecting people with community resources and opportunities to fulfill dreams by working with organizations such as Dream Foundation and Hospice Education Institute.

Betsy looks forward to being able to work on her health care experience enhancing and supporting people and families impacted by ALS in Central Oregon. Please join us in welcoming Betsy to our team. She can be reached at BetsyPaige@alsa-or.org or by calling 541-977-7502.

Betsy moved to Central Oregon one year ago with her husband, and two young boys aged 2 and 6 after spending 3 years in Denver, Colorado. Betsy has had the opportunity to work with people in an Adult Day Health setting facilitating various groups and activities including art, singing and spirituality and care coordination. Betsy worked as Medical Social Worker in Seattle and Harborview Medical Center assisting people with community resources, long term planning, advance directives and offering crisis support in the intensive care unit.

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Shana found visiting renaissance fairs, local wineries, cornmats, skating rinks, and the coast throughout most of the year. She also has a passion for the vintage things in life and enjoys old-fashioned music, ballroom dancing, and collecting antique odds and ends. An animal lover, Shana loves meeting pets and currently has two feline “practice children” of her own.

Shana feels honored to be a member of the ALS community. She is dedicated to assisting our people living with ALS and their families with supporting access and communication through their journey. To learn more about assistive technology or schedule an appointment for a personal consultation, contact Shana directly at 503-238-5559 (ext 4) or ShanaTognazzini@alsa-or.org.

Colton Allen, living with ALS in Talent, Oregon

My name is Colton Allen and I was diagnosed with ALS in June 2008. I was 28 when I was diagnosed with ALS. Like so many others with this disease, getting the diagnosis took forever; it was almost a year from my first doctor visit to the diagnosis.

The diagnosis was a shock.

I was a strong and healthy athlete, and had been playing hockey my whole life. But we knew something was wrong. My wife, Tiffany, and I had been married just two years and had decided to start a family. She was actually pregnant when I got the diagnosis. We now have a beautiful daughter named Etta, who just turned three.

Things for me have changed dramatically in the past four years. I can barely eat, because my arms can’t raise my fork to my mouth, I need help showering and getting dressed and I have to use a wheelchair if I want to walk anywhere farther than around my house. I haven’t worn my hockey skates in years, and had to apply for disability because I was no longer able to work in my profession as a timber framer.

Resources for Military Veterans, Families and Survivors

People who have served time in the military have a higher risk of developing ALS than those who have not served time.

Because of the advocacy efforts in the ALS community led by our Association’s Public Policy Department, veterans with ALS are now considered 100% service-connected.

If you have at least 90 days of continuous active military duty and have the diagnosis of ALS, you and your family are eligible to receive full VA benefits.

These may include:

- Monthly compensation
- VA healthcare benefits
- Insurance benefits for dependents
- Home adaptations
- Automobile grants
- Adaptive equipment
- Clothing allowance
- Aide and attendance allowance

If you are a survivor of a military veteran with ALS, you may also be eligible to receive VA benefits.

Contact us today at info@alsa-or.org to learn more about what might be available to you and your family.
We know one thing. We are not alone. This September, we Walk to Defeat ALS®

We’re all in this fight together. We are part of the Walk to Defeat ALS® for many reasons – hope, love, research, support, advocacy, making a difference, to honor and remember. But the number one reason! We walk because we can.

Being part of the Walk to Defeat ALS® is your event. You can register as an individual. You can start a team. You can join one. Your team can be a team of two people or two hundred. You can raise thousands of dollars or just come and help raise the much-needed awareness that the Walk brings. Whatever you need the Walk to be, it can be. And, our staff at The ALS Association can help make it that way. So, register today.

There’s no cost to participate and we want as many people as possible to be part of this event - aunts, uncles, kids, coworkers, church members, friends, neighbors, and even dogs. If you’ve been part of this inspiring event in the past, you know that it’s something that you just don’t want to miss.

This year, you can be an important part of raising over $700,000 to fund crucial services and programs for people living with ALS and their families. Your fundraising also supports internationally directed research and national public policy initiatives. It really is the event that each dollar and every person makes a big difference. Together, our impact will be incredible.

Attention! Who wants to be the recipient of this awesome, snazzy, cool t-shirt? If you raise your hand, then you are up for the challenge! Registered participants who raise a minimum of $25 will be a happy owner of this awesome t-shirt. Contact us to get registered today!

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 the 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. We promise. It’s easy. And, we want to help. We can’t wait to see you in this snazzy t-shirt!
The leader in global ALS research

All of the research sponsored by The ALS Association has been aimed at creating possible treatments for the disease. "Our TREAT ALS research program is focused on finding translational research that takes good ideas from the lab and translates them to the clinic, where human beings can access experimental therapies," Brujin says. "Our hope is that a treatment to slow ALS is coming soon."

The Association's global research effort has helped increase the number of scientists committed to working on ALS, advanced new discoveries and treatments, and shed light on the complex genetic and environmental factors involved in the disease.

Among the significant research milestones so far:
- "The groundbreaking discovery of a genetic abnormality that is currently the most common cause known of both ALS and Frontal Temporal Dementia.
- A recent breakthrough in familial ALS research that shows how two proteins work together to batter the survival of motor neurons.
- The discovery of the ALS gene SOD1, which scientists say is responsible for 20 percent of all inherited ALS cases.
- The discovery in 2009 of ALS-TFR2, a gene scientists say is responsible for about 5 percent of all inherited ALS cases.
- The first clinical trial of ISIS-SOD1, a new drug that specifically targets the SOD1 gene.

Locally, The Association's partnership with the Providence ALS Center — a unique collaboration between Providence Brain Institute, The Oregon Clinic and The ALS Association — focuses on enrolling people living with ALS in clinical trials to assist international research initiatives. In addition, the Oregon and Southwest Washington Chapter regularly supports the national research effort.

"We are excited to contribute to a national and international coordinated research effort," says Lance Christian, the local chapter's executive director. "We know that by pulling together our national effort, we can fund the most promising research wherever it is occurring, and that a treatment will come sooner if we all work together."

"We are proud to be supporting research that will lead to a cure for this challenging diagnosis.

Be a part of the search to find the cause, treatment and cure!

The National ALS Registry is OPEN! Enrollment Underway!

Every person currently living with ALS can be a crucial part of creating a world without ALS. Every person living with ALS in the United States can self-enroll in the National ALS Registry. The National ALS Registry may be the single largest ALS research project ever created and is designed to identify ALS cases from throughout the entire United States. 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 (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. We strongly encourage every person with ALS to participate in this effort.

Visit www.cdc.gov/ALS to sign up today!

Let us know if you need help and we can walk you through the process.

Contact us at info@alsa-or.org or by phone at 503-258-5559.

Local delegates gather in Washington D.C. to lobby for change.

Each year, a band of delegates from Oregon and SW Washington travel to Washington D.C. to take part in The Association’s National Public Policy and Research Conference. Over 900 people across the country gather together to become effective advocates, learn the latest in ALS research, and during a candlelight vigil held in Freedom Plaza, honor and remember those living and who have lived with ALS. Most importantly, all attendants congregate on Capitol Hill, sharing their story and encouraging continued support of ALS research. The three priorities that were focused on this year are: 1. Approve $10 million to continue funding the National ALS Registry, 2. Appropriate $10 million to continue the ALS Research Program at the Department of Defense, and 3. Enact the MODDERN Cures Act, H.R. 3497.

Steve (diagnosed with ALS in 2011) and Bo Stern of Bend, Oregon participated in the conference. Bo reflects, “As a family living with ALS, we were honored to spend time with so many others fighting the same fight and to learn more about the search for a cure. It was stunning to see so many wheel chairs, storming Capitol Hill to speak on behalf of all those who have or will face this horrific disease in the future. I think our congressional representatives discovered the truth about people affected by ALS: they are brave, determined and strong in all the ways that matter most. We were so thankful to be a part of this amazing event.”

Development Director, Aubrey McCauley, also attended the conference along with public policy volunteer, Carolyn Anderson, chapter board member, Beth Twist and volunteers and advocates John and Barb Deeming.

Exciting and hopeful news came from the conference, when Dr. Traynor, a top-notch geneticist, projected that within the next five years, the genetic code for ALS is solvable. For a disease that has been without progress for years, these are more than exciting times. Unlocking the genetic secrets of ALS will lead to treatments and ultimately, a cure for ALS.

For a disease that has been without progress for years, these are more than exciting times. Unlocking the genetic secrets of ALS will lead to treatments and ultimately, a cure for ALS.

“The updates we received at this conference were some of the most promising we have heard in some time. The genetics of ALS has attention at this time because of the technology we have to study it,” recalls McCauley. “It is of the utmost importance that all people currently living with ALS enroll in the National ALS Registry. This registry is the largest ALS research program available and will help count the actual number of diagnoses and more importantly, identify potential environmental factors that play a role in the disease. Help make your voice heard on important issues. More information or would like help with registering are encouraged to contact our chapter. These are promising times for the ALS research world – but everyone has to do their part.”

During the meetings on Capitol Hill, stories were told. Bo and Steve told about their family learning to live with the disease. Deeming told her brother’s story. Twist and Anderson honored their fathers. McCauley shared the initiatives that were of severe importance. Hands where shaken, tears were shed and a sense of action was created in doing more for the ALS community. All in all, a successful day on the Hill.

Within a few days of the conference, exciting news was shared with advocates that $7.5 million was approved for the ALS Research Program. Not the $10 million that was asked for, but a 17% increase from last year, and a direct reaction to their amazing efforts. Every voice counts and every voice needs to be heard. The ALS community deserves it.
Thank you to our 2012 Year-Round Partners: Fred Meyer, Northwest Medical and Wells Fargo

**Hitting the slopes causes an avalanche of support.**

The inaugural Ski to Defeat ALS broke more than one record. Being a first time event, a lofty goal of raising $100,000 was set and the Ski to Defeat ALS committee went to work. Over regular meetings, ideas came real and the event came to life. On April 14, 2012, over 250 skiers, snowboarders and guests came together and memories were made. Together this amazing group of people collected over $160,000 – blowing our lofty goal out of the water!

Perhaps one of the most unexpected yet remarkable moments came from The ALS Association’s partnership with Mt. Hood Meadows and Oregon Adaptive Sports. Nine people living with ALS were able to transfer from their wheelchairs to an adaptive sit-ski, and were given the opportunity to feel the wind in their face as they were able to ski down the mountain again. For some, it was their first time skiing.

**Kudos to the top fundraising teams:**

<table>
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<td>Fred Noble</td>
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**Most Vertical Feet for Individual:**

- Dale Parshall, SVSC, 65,434 ft

**Most Vertical Feet for Team:**

- Team Fredinator, 731,412 ft

**Top Fundraising Team:**

- Team Fredinator

**Top Individual Fundraiser:**

- Fred Noble

**Cycling for a Cure**

Covered bridges, expansive farmland, and a reason to throw your legs over a bike and get out on the open road. Combine these with a fully-supported route and exciting and original rest stops and you’ve got the inaugural Ride to Defeat ALS. For just $35, riders can select their choice of a 25, 50 or 100 mile challenge. Children are just $15. Each registered participant must raise at least $150 by the date of the event. This might sound like a big number, but chapter staff is available to help participants reach their goals. Already, participants have raised thousands of dollars leading up to the ride.

The overall goal for the Ride to Defeat ALS is to raise $100,000 to directly benefit local patient services and more. If everyone does their part, this lofty goal will be reached!

In addition to the picturesque landscape that each ride option provides, participants will be treated to a variety of rest stops along the way. If you’re cycling through Willamette Farms on the 50-mile and 100-mile rides, you’ll be treated to fresh, local strawberry shortcake. If you’re participating in any of the routes, you’ll be treated to fresh pies by Bauman Farms.

The routes each offer something different. If you’re looking for a flat, family friendly option, consider the 25 mile route. Even this option will take you through some beautiful farmland and the wind in your hair. The 50 mile route is a little more challenging, offering something tasty at Bauman Farms. Don’t forget to bring your camera because you’ll certainly want to capture this experience. Susan C., team captain of The Flying Mavericks, recently rode this course to check it out. She was blown away by the route!

“The Ride to Defeat ALS 25 mile challenge is not about the finish but the journey. Beginning in Mr. Angel, my husband Scott and I went on a beautiful ride discovering Oregon’s agriculture, diversity and beauty. From oregano and hop fields to dairy and lamb farms, our senses were piqued. This ride allows you to enjoy the scenic diverse beauty Oregon offers and a smooth ride to boot!”, says Susan.

“For any of us who have had family or friends with ALS, we are often without words to fully convey our feelings,” says Jordan Schnitzer, the event’s honorary co-chair. “The local chapter of The ALS Association steps in with the right support and encouragement to make a difference.”

Schnitzer ensured the local chapter far exceeded their goals for what the chapter calls the “Make a Difference,” more often known as the special appeal. During a memorable moment at the end of the appeal, Schnitzer approached the stage and with a business counterpart, contributed an additional $12,500 to the cause. His generous donation rounded the total to an even $150,000 making it by far the most successful appeal the chapter has seen.

The 10 Year Anniversary Bash was written and supported by:

- Harold & Arlene Schnitzer CARE Foundation

10 Year Anniversary Bash (continued from page 12)

**Visit www.OregonRideToDefeatALS.org to register today.**

**Hitting the slopes causes an avalanche of support.**

The inaugural Ski to Defeat ALS broke more than one record. Being a first time event, a lofty goal of raising $100,000 was set and the Ski to Defeat ALS committee went to work. Over regular meetings, ideas came real and the event came to life. On April 14, 2012, over 250 skiers, snowboarders and guests came together and memories were made. Together this amazing group of people collected over $160,000 – blowing our lofty goal out of the water!

Perhaps one of the most unexpected yet remarkable moments came from The ALS Association’s partnership with Mt. Hood Meadows and Oregon Adaptive Sports. Nine people living with ALS were able to transfer from their wheelchairs to an adaptive sit-ski, and were given the opportunity to feel the wind in their face as they were able to ski down the mountain again. For some, it was their first time skiing.

**Kudos to the top fundraising teams:**

<table>
<thead>
<tr>
<th>Team</th>
<th>Fundraising Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fredinator</td>
<td>$56,248</td>
</tr>
<tr>
<td>Cerus Industrial</td>
<td>$10,270</td>
</tr>
<tr>
<td>Parry’s Angels</td>
<td>$5,367</td>
</tr>
</tbody>
</table>

**And the top fundraisers:**

- Fred Noble – $29,337
- Patty Belcher – $6,392
- John Peterson – $5,000

**Most Vertical Feet for Individual:**

- Dale Parshall, SVSC, 65,434 ft

**Most Vertical Feet for Team:**

- Team Fredinator, 731,412 ft

**Top Fundraising Team:**

- Team Fredinator

**Top Individual Fundraiser:**

- Fred Noble

**Cycling for a Cure**

Covered bridges, expansive farmland, and a reason to throw your legs over a bike and get out on the open road. Combine these with a fully-supported route and exciting and original rest stops and you’ve got the inaugural Ride to Defeat ALS. For just $35, riders can select their choice of a 25, 50 or 100 mile challenge. Children are just $15. Each registered participant must raise at least $150 by the date of the event. This might sound like a big number, but chapter staff is available to help participants reach their goals. Already, participants have raised thousands of dollars leading up to the ride.

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10 Year Anniversary Bash (continued from page 12)

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GIVING

Supporting the work of The ALS Association through estate planning

A Charitable Remainder Trust is a special tax-exempt irrevocable trust arrangement written to comply with federal tax laws and regulations. You transfer cash or assets (especially appreciated assets) to the trust and may receive income for life or, if you choose, a certain term of years (not to exceed 20). In fact, the income can be paid over your life, your spouse’s life and even your children’s and grandchildren’s lives.

Please consider supporting the vital mission of The ALS Association Oregon and SW Washington Chapter through naming them in your estate planning. The income can be paid over your life, your spouse’s life and even your children’s and grandchildren’s lives.

Looking Back on the Last 10 Years

1990s – 2001: Volunteers dream of creating a local organization to help people with ALS. The Assisi Technology Program is created. A serving world without ALS. The sky is the limit.

2002: The Assisi Association Oregon and SW Washington Chapter is founded. The first Walk to Defeat ALS® in Portland is held in September. The chapter’s partnership with The Oregon Clinic and Providence Health & Services creates the Providence ALS Center. The first Spa Day is held in Salem.

2003: The chapter is serving roughly 50 families. The Salem Support Group is started, as is the Medical Equipment Loan Program and Respite Care Program.

2004: The first major gift of $300,000 helps grow the chapter’s staff and programs. The chapter sends its first delegation to Washington, D.C., for the National ALS Advocacy and Research Conference. The first Walk to Defeat ALS® expands to SW Washington. The Providence ALS Center is certified as a Center of Excellence and offers its first clinical trial. Medical Equipment Loan Programs are started in Central and Southern Oregon.

2005: The chapter’s partnership with The Oregon Clinic and Providence Health & Services creates the Providence ALS Center. The first Spa Day is held in Salem. The Providence ALS Center is certified as a Center of Excellence and offers its first clinical trial. Medical Equipment Loan Programs are started in Central and Southern Oregon.

2006: The chapter begins offering regular professional education programs. The Annual Dinner and Gala raises more than $300,000. Support groups are started in Bend and Eugene. The Walk to Defeat ALS® expands to Central Oregon, Southern Oregon and the Willamette Valley.

2007: The chapter adds staff to serve Southern Oregon, Central Oregon and the Willamette Valley.

2008: Walk to Defeat ALS® expands to SW Washington. The Providence ALS Center is certified as a Center of Excellence and offers its first clinical trial. Medical Equipment Loan Programs are started in Central and Southern Oregon.

2009: The chapter is serving more than 300 families per year. The chapter is serving more than 300 families per year.

2010: Walk to Defeat ALS® in Oregon and Southwest Washington raise more than half a million dollars.

2011: A Yamhill County Support Group is launched.

2012: The chapter celebrates its 10th anniversary with a Bash that raises more than $400,000. The first Ski to Defeat ALS is held in April, and the first Ride to Defeat ALS is planned for July. The chapter significantly increases its regular contributions to nationally directed, cutting-edge ALS Research.

Coming Soon: A treatment and cure for ALS!

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:

- Eugene Barrett, Bob Bennett, Robert Borghorst, Randall Cadmus, Velma Deben, Linda Donnelly, Shawna Dougerty, Jeff Everet, Margaret Gires, Chuck Gould, Lonna Gustavson, Ken Hintz, Elena Krym, Joe Kuling, Juanna McCrery, Michael Patterson, Lewis Peterson, Nadine Shepard, Carla Simantel, Paul Speck, Ted Suttmeier, Merlie Thompson, Jeff Tianno, Sheila Watson

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

The ALS Association has made every effort to ensure the accuracy of the numbers, 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 or our records can be changed and updated.

The Assisi Technology Program is created. A serving world without ALS. The sky is the limit.

We need volunteers to do everything from pre-event coordination to day of activities such as taking photos, staffing the Kids’ Zone, assisting at rest stops, handling registration and so much more! Volunteers will receive free entry to the event, a snazzy Volunteer T-shirt, and meals.

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The 10th Annual Walk to Defeat ALS® for our chapter is coming up in September and this year is shaping up to be one of the best yet!

Central Oregon Walk – Bend, OR – September 8, 2012
Southern Oregon Walk – Medford, OR – September 9, 2012
State Capitol Walk – Salem, OR – September 15, 2012
Willamette Valley Walk – Eugene, OR – September 16, 2012

We need volunteers to help with setup, traffic control, snack distribution, registration and much more. A few hours of your time will go a long way in helping to make the Walk to Defeat ALS® our largest fundraiser and awareness event, a huge success!

Want to get involved? Help by Volunteering your time and skills for our upcoming events!

Our inaugural Rides to Defeat ALS® will debut on Saturday, July 14, 2012 in Mt. Angel, Oregon.

Contact us at volunteer@alsa-ore.org with Rides Volunteer in the subject line if you are interested.

Honoring 10 Years of Service

The Assisi Association Oregon and SW Washington Chapter honors 10 years of service to the community. As we look back on all of the accomplishments of a decade of work, it is important to remember where we, the local ALS community, started.

Ten years ago, a dedicated band of volunteers formed the local chapter of The ALS Association. These families and friends of people with ALS worked diligently because they personally understood the challenges and resources that were needed to live with ALS. Their mission was to offer FREE local resources to ease the way for newly diagnosed families.

Before the local chapter of The ALS Association was formed, there was no central hub where families and people with ALS could look for information and support. There were no support groups, no ALS-specific multi-disciplinary clinics and very little professional support for people living with ALS. People had to face ALS alone.

Today, things are different. There is now professional support, resources and ALS-specific health care across the region to help families find their way. Today, a family receiving an ALS diagnosis can count on a community of supporters to help them understand the road map of ALS — where the forks in the road are, what’s around each bend, and where the management road leads.

Over the last decade, The ALS Association and its supporters have:

• Served more than 1,000 families living with ALS across Oregon & Southwest Washington;

• Helped more than 450 people with ALS be able to communicate and use computers through our Augmentative Communication and Assistive Technology Program;

• Launched thousands of pieces of needed medical equipment to families. From power wheelchairs to grab bars, these tools have helped hundreds of families maintain their independence;

• Sponsored hundreds of ALS Support and Education groups, where families living with ALS can gather to learn about ALS and support one another;

• Funded more than $300,000 of in-home care through our Respite Care Program;

• Founded and funded the Providence ALS Registry;
SUPPORT GROUP SCHEDULE

Portland Metro Region
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.

3rd Thurs. of every month, 4:00pm – 5:30pm
Note: this group is for family caregivers only.
Legacy Meridian Park Hospital,
Health Education Center – Room 106
19300 SW 65th Ave., Tualatin, OR
For more information and directions contact:
Lance Christian at 503-238-5559 or
toll free at 800-681-9851

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

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

State Capitol Region
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

Central Oregon Region
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 Rinning at 541-977-7502

Southern Oregon Region
3rd Thurs. of every month, 2:00pm - 3:30pm
Rogue Valley Medical Center Campus, Smullin Center, 2825 East Barnett Rd, Medford.

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

Southwest Washington
2nd Wed. of every month, 4:00pm - 5:30pm
Memorial Campus of SW Washington Med. Ctr.
Health Connection Room on 2nd Floor
100 E. 33rd Ave, Vancouver, Washington
For more information and directions contact:
Lance Christian at 503-238-5559
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