Dear Friends,

It is hard to believe that in a few short months we will be turning our calendars to 2012. As we near the end of this year, we pause to think about where we have been and where we are headed. It was just ten short years ago in 2002, our Founding Director, Cindy Burdell and a dedicated group of board members and volunteers affiliated with The ALS Association and launched the Oregon and SW Washington Chapter.

Hard work and perspiration by these early pioneers went into creating and funding the chapter that families living with ALS take for granted today. Standing where we are today, it’s hard to imagine a world without our local chapter and local, hands-on support for people living with ALS and their families. That hard work continues on…

For the last decade, The ALS Association has been a beacon of hope and support for families living with ALS across Oregon and SW Washington. During that time, our chapter has had the opportunity to accomplish much, and tackle many meaningful issues.

- We have served over 750 families living with ALS across the region.
- We have helped over 450 people with ALS be able to communicate and use computers through our Augmentative Communication and Assistive Technology Program.
- We have loaned thousands of pieces of needed medical equipment to families. From power wheelchairs to grab bars, these tools helped hundreds of families maintain their independence.
- Our local chapter has sponsored hundreds of ALS Support and Education Groups where families living with ALS can gather to learn about ALS and support one another.
- We’ve been able to fund more than $380,000 of in-home care through our Respite Care Program.
- We’ve proudly co-founded and funded the Providence ALS Center in collaboration with The Oregon Clinic and Providence Health and Services. This is the only Multidisciplinary Center in the region, certified by The ALS Association.

continued on page 3
Thank You Caryn, Welcome Myrya!

Every non-profit, including The ALS Association, has the same administrative needs as any small business. From sending out thank you letters to ordering supplies to balancing our books, the list of tasks is endless. We are grateful to have dedicated and competent staff to meet this need.

We want to say thank you to Caryn Porter for over three years of service to The ALS Association. Caryn retired at the end of August, but continues to help the chapter with some of our database coordination needs. Since retiring, Caryn has been spending quality time with her granddaughter and she also adopted a rescue dog, Molly. Thank you Caryn!

We are happy to welcome Myrya Molkentine to our team as our new Bookkeeper/Database Coordinator. Myrya has extensive experience with bookkeeping and database systems. When she is not balancing our books, her passion is community organizing. From coordinating local community gardens to neighborhood-based soup kitchens, Myrya is dedicated to making the world a better place. We are thrilled to have her on our team. Welcome Myrya.

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.

May 29th, 2011 – September 24th, 2011


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

SAVE
the DATE
SATURDAY, MARCH 10, 2012
OREGON CONVENTION CENTER, PORTLAND, OREGON
FOR OUR 10TH ANNIVERSARY BASH!

If you would like to be kept in the loop with details, please contact us at gala@alsa-or.org.
Cover Article continued from page 1

- We’ve created dozens of professional education programs for doctors and healthcare professionals working with ALS.

- Our professional staff has had the opportunity to guide scores of families through challenging legal, financial, workplace and healthcare decisions.

- We’ve advocated to Congress for the creation of support resources for people living with ALS like the 24 month Medicare waiver, presumptive Social Security Disability eligibility for people with ALS, service connected disability benefits for veterans, and the ALS Registry.

- And not least of all, our local chapter has raised money and funded research that has made progress in understanding ALS in the search for treatment and a cure.

Of all these accomplishments, perhaps the thing I am most proud of is that for each newly diagnosed family facing the unknown challenge of ALS, we could tell them this: “You are not alone. There is whole community of people here to support you.”

On behalf of the board and the staff of The ALS Association, I am pleased to announce that in January we will be kicking off a yearlong 10th Anniversary Celebration for the chapter. Throughout 2012, we will be launching new events and adding some special twists to some of our old favorites to celebrate where we have been. Look for special announcements after the New Year on the exciting ways that we’re celebrating our 10 years of service.

In the meantime, we have a challenge for you. We need your help thinking about the next ten years. We need you to think about a cure for ALS. We need you to think about what supports families need to cope until there is a cure. What more can we do to help families facing ALS?

I would like to challenge you to write me directly and tell me your hopes and dreams for The ALS Association.

Please send a letter or email to me and complete this phrase:

In the next ten years, I hope the ALS Association...

Your feedback will drive the direction of our chapter for the years ahead.

Sincerely,

Lance Christian, LMSW
Executive Director
LanceChristian@alsa-or.org

Visit our webpage at www.alsa-or.org to learn more about how to follow us online!
NW Oregon - SW Washington

Services Coordinator Sarah Greenstein and Lance Christian continue to support PALS and their families through home visits, facilitating support groups from Salem to Vancouver, and meeting with families at the Providence ALS Center. Together, they conducted home visits with 20 newly diagnosed families, and numerous families continuing to live with ALS over the past few months.

In August, Sarah traveled to Seattle to attend a two-day Medicare workshop sponsored by the National Medicare Training Program and the Centers for Medicare and Medicaid Services to learn about Medicare updates. An important tidbit from the workshop: keep in mind that the new Open Enrollment period deadline for making changes to your Medicare plans has changed, and is now October 15-December 7th. We are here to answer questions and guide you in the right direction if you need it.

Summer also brought an opportunity to reach out and connect with people from local programs including SHIBA (Senior Health Insurance Benefits Assistance), the Multnomah County Aging and Disability Services Helpline, and Multnomah Project Independence. By strengthening our relationship with these resources, not only do we become more aware of the supports that exist in our community to help our PALS and their families navigate through the challenges brought on by ALS, but also, these organizations become more familiar with ALS and how they can effectively serve our community.

For those families who live in the Yamhill/McMinnville/Newberg areas, please contact Sarah (ext. 5) if you are interested in attending a “Fall Meet-Up” in your area in mid-October. Look for more details soon!

As always, we are grateful for our partnership with CARE Medical. Without the generous support of this family-owned medical equipment company, we would not be able to serve over 100 families through our Medical Equipment Loan Program. From power wheelchairs to bath benches, we are providing needed equipment to families at no cost.

On a personal note, Sarah Greenstein would like to share that she experienced for the first time the bittersweet moment of coming together in support group to honor and recognize the passing of a dear one from ALS. Sarah continued to be inspired by the strength, perseverance and love found in each of our families living with ALS as caregivers and PALS were faced with challenges unique to the summer season such as balancing care-giving with caring for children home from school, traveling and making memories with increased disability, and adjusting to a new daily reality while mourning the loss of certain favorite activities.

Our Assistive Technology Services Coordinator, Betts Peters, continues to be busy working with PALS and families in their homes and at the Providence ALS Center. This fall, she will be participating in several educational events for healthcare professionals, working to raise awareness of ALS and augmentative/alternative communication. In October, she will teach a seminar on communication device mounts for speech-language pathologists and occupational therapists in Eugene. In November, she will present on augmentative/alternative communication techniques at CARE Medical’s annual CARE Fair health-care conference. She will also be a guest speaker for the fall augmentative/alternative communication course at Portland State University, teaching future speech-language pathologists about ALS and the communication needs of PALS.

Central Oregon

Since our last newsletter update, we have had two additional ALS clinics in Central Oregon both held at The Center with Dr. Ugalde’s assistance and overview. Staff at The Center has been so accommodating and patient with us as we take over their space on those Friday afternoons. We do appreciate their welcoming attitude. The location makes it easy for PALS neurologists to either fit in to the day’s schedule or attend the teaming following. Our core team continues to meet monthly.

The August support group heard from Shannon Bennett of At Home Care Group. She explained the difference between Home Care and Home Health as well as providing information on how her organization works with the Veterans Administration. Shannon also created a special article in their monthly electronic newsletter during ALS Awareness month to bring awareness to the disease. Our meetings during the summer also got us ready for the Walk to Defeat ALS® with Meagan Lancaster attending our meeting during June and Carolyn Anderson and Joan Anderson making sure we had posters and up to date information. We watched in awe as Steve Stern’s family rallied a huge Walk team and raised over $20,000. The support of the Stern family and their dedication to serving others with ALS is inspiring and humbling.

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continued on the page 19
Caregiver call bells and emergency alert systems are an important safety net for many people with ALS. You may need to alert your spouse when he or she is sleeping in another room or working out in the yard. Or, you may need a way to call for help if you fall while home alone and are unable to get up. The wide variety of options available means that almost anyone, regardless of their physical abilities, can have a way to call for help in an emergency. Read on for suggestions:

**When you need to call from another room**

Wireless doorbells are a simple, inexpensive solution for people who have relatively good hand function and can easily press a small button. The PALS can keep the button unit nearby (in a pocket, on a table, or attached to a wheelchair arm), and the battery-operated chime unit can be placed anywhere in the house or even taken out into the yard. You may purchase a wireless doorbell at your local hardware store, or from a website. If you go to shopping.google.com and search for “wireless doorbell,” you will find a list of options starting at around $10. You might also try www.gadgetshack.com, which offers models with intercom functions, and some with ranges of up to 1000 feet. Some models may have a variety of alternate button styles available, including buttons that are larger and easier to activate.

Some PALS may need a specialty call bell that can be activated without the use of the hands, such as the PA-1 Alarm from MedLabs. The PA-1 can be used either with Med Lab's E-Z Call switch (a large, angled plate switch with clips to attach it to bedsheets or clothing) or with any switch or button of your choosing (note that you will need an adapter to use other switches). These special switches can be activated with movements of the head, legs, or arms, or almost any body part the PALS can reliably move. The switch is plugged directly into the alarm box, so the alarm will typically be in the same room as the PALS, although you could buy an extension cord to allow the box to be placed in a hallway or other location. The alarm sound is very loud. You can learn more about the PA-1 Alarm and E-Z Call switch at www.medlabsinc.com.

**For more information about any of these options or for help finding a call system to meet your needs, please contact Betts Peters at 503-238-5559, ext. 4, or BettsPeters@alsa-or.org.**

Other options include baby monitors, walkie-talkies, and alarm buttons built into other devices such as power wheelchairs or communication devices. Please contact Betts Peters for advice on call systems that may work best for your specific needs and abilities.

**When you are home alone**

There may be times when you are home alone and need a way to call for help in an emergency. Although the phone is a good option for some people, it may not always be within easy reach if you have a fall or another type of emergency that affects your mobility. Many PALS have difficulty holding or dialing a phone, and need an alternative way to call for help.

Medical alert systems such as Lifeline or myHalo can be activated by pressing a button worn on a lanyard or wristband (alternative buttons are available for people with impaired hand function), or by an automatic fall detection feature that works even if you are unable to press the button yourself. When activated, the system contacts an operator who can communicate with you via speakerphone, if possible. The operator has access to a list of phone numbers that you provide (these can be family members’ or friends’ cell phones, neighbors, or whoever you like), and will call each number on the list until someone answers and can come to your assistance. If you need urgent help or there is a medical emergency, the operator will call 911 for you. You can learn more about Lifeline and myHalo at www.lifelinesys.com and www.halomonitoring.com, respectively.

Both Lifeline and myHalo will work only around the home, and require either a land-line telephone or broadband internet connection. For those who need a mobile emergency call system, there are specialized cell phones with a built-in emergency button. When the emergency feature is activated, the phone will automatically call and send a text message to your emergency contacts.

Whether you are at home or on the go, home alone or just across the hall, call bells and emergency alert systems are an important way to protect yourself and provide peace of mind for your loved ones.

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**Assistive Technology Corner: Call Bells & Emergency Alert Systems for PALS**

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.

Thank you to our 2011 Year-Round Partners: CARE Medical, Northwest Medical & Fred Meyer
How Much “Will” Power Do You Have?

Lou Libby, MD
Vice President, Board of Directors
The ALS Association Oregon and SW Washington Chapter

I hate going to my “estate attorney” and looking at my will. But I do it every 5-10 years because my late father, my long standing advisor about business affairs, always told me to do it. I hate it because it can be expensive and it makes me talk about things I do not like to think about – death – especially my own and my wife’s. But it is a vital and important thing to do and frankly it has served me well. My parents were thoughtful in their estate planning and that has helped my children go to college without debt but also helped my parents’ favorite charities - something they were passionate about.

Of course as a physician, I have an underdeveloped business sense but I know that if I do not make some plans, Uncle Sam (and his greedy cousin, the State of Oregon) will take as much of my money as they can when I die. And the rules seem to change so often, and the options to avoid death taxes change so often, that only a lawyer can understand it all and advise you on what to do.

But the real reason that I go to the estate attorney is to help those people and causes that have been my passion for many years. Of course, number one on that list is my family – wife, children and hopefully, eventually, some grandchildren. But in addition, I am passionate about my profession and ALS has been at the very top of my professional concerns and something I feel very strongly about. This is why I have been involved in The ALS Association since its inception here in Oregon and SW Washington. I am passionate about providing adequate support to improve quality of life for those living with ALS and I am equally passionate about creating a world without ALS.

So with the help of my estate attorney, I have been able to arrange to make sure my wife and children are reasonably financially secure and in addition, I have arranged to support The ALS Association Oregon and SW Washington Chapter in hopes that someday there is no need for any of us to worry about ALS! That is the dream and I am doing everything I can now, and after I am long gone, to help us reach that goal. And as a nice little bonus, my estate attorney has told me that I am going to save money by doing this - something about taxes that I will never understand!

With this, I encourage all of you to see an estate attorney and decide what is passionate in your life and make sure you do what you can to support that cause (as well as your family) after you are gone. Even if I hate going to my estate attorney, it certainly feels good to know that I am doing one extra thing long after I am gone to help one of my passionate causes. Do you have the “will” power to go to your estate attorney and get it done? I hope so.

Feel free to contact our local chapter if you have questions, need a referral to an estate planning lawyer who is experienced in dealing with ALS, or to simply let them know that you have already included them in your plans.

Please follow up with Lance Christian, Executive Director, or Aubrey McCauley, Development Director.

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 ext 1.

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

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 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 names of members in the future to this ever-growing list of committed individuals.
Honoring Randy: An ALS Promise.

When Randy Cadonau passed away from the effects of ALS in the spring of 2011, the ALS community, Portland and the whole world lost a generous and kind soul. Most importantly, Randy’s family lost their beloved husband, brother and uncle.

Anyone who knew Randy or knows the Cadonau family knows that they make a big difference in the world. From the time of his diagnosis, Randy’s family rallied behind him in his fight with ALS. The entire family took up Randy’s banner and has shown incredible love and dedication to help other families with ALS.

"Randy was an incredibly kind and generous man. He and his family have a ‘can do’ spirit. They have made it clear that they are in the battle with ALS for the long run, both to help other families living with ALS and for a cure,” says Lance Christian, Executive Director for The ALS Association Oregon and SW Washington Chapter.

The ALS Association Oregon & SW Washington Chapter is pleased to announce that the Cadonau family has established the “Randy Cadonau Promise Fund” with a generous two year pledge of $50,000. This fund, with its interactive website and memorial, will act as a perpetual beacon of hope from Randy to his community and all people with ALS.

The Randy Cadonau Promise Fund site is in development and will be launched shortly at: www.alspromise.org. For more information on establishing a Promise Fund for your loved one with ALS, please contact Lance Christian at the chapter office 503-238-5559 ext 1 or LanceChristian@alsa-or.org.

Support the ALS community by participating in our Monthly Giving Circle!

Monthly giving through our chapter’s headquarters offers a convenient way for you to support the important work of our Association in your community throughout the year. Members of our Monthly Giving Circle provide The ALS Association with a much needed dependable stream of income that we use to provide support groups, find resources for people living with ALS who need them, maintain and grow our medical equipment loan closet and support national and local research efforts – so eventually, there will be no such thing as Lou Gehrig’s Disease.

On a monthly recurrence, your contributions are charged to your credit card, or debited from your checking account, on a specified day of the month that you request. At any time, you may change your gift amount or payment method or cancel your participation.

To sign up, please contact Aubrey McCauley, Development Director, at AubreyMcCauley@alsa-or.org or 800-681-9851 ext 3.

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.
New Genetic Mutation Identified: the Most Common Cause of FTD and ALS Accounting for as Much as One Third of All Familial ALS

Two independent studies, both funded by The ALS Association, have found a genetic abnormality that, according to researchers, is the most common cause of Amyotrophic lateral sclerosis (ALS) and frontotemporal dementia (FTD). As reported in the recent online issue of the scientific journal Neuron, an unusual mutation was discovered, where a short DNA sequence is repeated many more times as compared to healthy individuals.

Using next generation sequencing in a study led by Bryan J. Traynor, M.D., Laboratory of Neurogenetics, National Institute on Aging, the team identified a GGGGCC hexanucleotide repeat within the non-coding region of a gene on chromosome 9p21. This repeat accounts for nearly 50% of familial ALS cases in Finland and more than a third of familial cases in other European populations.

The identification of the same genetic abnormality was independently made by a group at Mayo Clinic in Jacksonville, Florida led by Rosa Rademakers, Ph.D. and published in the same journal. The repeat of C and G (two of the four nucleotides that make up the genetic code) was found in a non-coding region of a gene called C9ORF72, which has no known function and its role in disease remains a mystery.

“We believe that when the defective gene is transcribed into a messenger RNA molecule, the expanded repeat section causes the RNA to bind tightly to certain proteins, forming clumps within the brain cells,” according to Dr. Rademakers. “By binding these proteins, the abnormal RNA may prevent these proteins from carrying out their normal functions in the cell.”

“This is tremendously exciting,” commented ALS Association Chief Scientist Dr. Lucie Bruijn, Ph.D. “These findings will significantly impact the field as we begin to understand more about the consequence of these changes to the disease process, aid our understanding of FTD and ALS, potentially provide a diagnostic tool, and enable the development of new therapeutic approaches.”

Stem Cell Therapy for ALS: Interim Data on Neuralstem ALS Phase I Trial Announced

Eva Feldman, M.D., Ph.D., Principal Investigator of the Phase I safety trial of Neuralstem Inc’s human spinal cord stem cells in ALS, presented primary and secondary endpoint data on the first 12 patients at the American Neurological Association’s annual meeting. The report indicates the procedure to be safe and some improvement in motor function.

“Eight out of ten living subjects in the trial showed lower extremity function scores that remained the same or improved after treatment,” commented Dr. Feldman. “Two out of ten showed continued decline of lower extremity function. The sample size and follow-up time are too limited to draw any conclusions, but we are encouraged by the safety profile of our approach.”

“We are pleased to hear the progress in the study and the encouraging safety profile in patients,” said ALS Association Chief Scientist Lucie Bruijn. “We look forward to learning more about the study results as it becomes available.”

The Phase I trial to assess the safety of Neuralstem’s spinal cord neural stem cells and intraspinal transplantation method in ALS patients has been underway since January 2010. Twelve patients have been transplanted in the lumbar region of the spine. The last of these was transplanted in April, 2011. The trial is designed to transplant up to 18 patients. After a required FDA safety data approval, the trial is expected to progress to include cervical injections for the last six patients.

New Research Points to Common Cause of ALS

In an article in the journal Nature, investigators from Northwestern University Feinberg School of Medicine have identified a new gene linked to familial ALS involved in the processing of accumulated proteins. This provides further support for abnormal protein handling as an underlying cause of ALS.

Optimal functioning of the neurons relies on efficient recycling of the protein building blocks in the cell. In ALS, it appears that the recycling system is abnormal. The cell can’t repair or maintain itself and becomes severely damaged. According to researchers, this breakdown occurs in all three forms of ALS: hereditary, which is called familial; ALS that is not hereditary, called sporadic; and ALS that targets the brain, ALS/dementia. Investigators have identified this new gene change in familial ALS with and without frontotemporal dementia.

This discovery provides further evidence that protein mishandling is a common target for ALS and important for the development of new therapies. Senior author Teepu Siddique, M.D., the Les Turner ALS Foundation/Herbert C. Wenske Professor of the Davee Department of Neurology and Clinical Neurosciences at Northwestern’s Feinberg School and a neurologist at Northwestern Memorial Hospital emphasized the significance of this finding bringing us closer to identifying new compounds regulating this pathway to slow or reverse disease progression in ALS.

“The identification of a new gene linked to familial ALS known to be involved in protein handling of the cell will open up a new avenue of research and bring us closer to understanding this process and what goes wrong in the disease,” commented ALS Association Chief Scientist Lucie Bruijn, Ph.D. “We look forward to follow-on studies that bring us closer to effective therapy for the disease.”

The discovery of the breakdown in protein recycling may also have a wider role in
Thank you to our 2011 Year-Round Partners: CARE Medical, Northwest Medical & Fred Meyer

Research Updates continued from the previous page

other neurodegenerative diseases such as: Alzheimer’s disease and frontotemporal dementia as well as Parkinson’s disease, all of which are characterized by aggregations of proteins. The removal of damaged or misfolded proteins is critical for optimal cell functioning.

Han-Xiang Deng, M.D., lead author of the paper and associate professor of neurology at the Feinberg School, commented that the study provides robust evidence that a defect in the protein degradation pathway causes neurodegenerative disease.

The ALS Association and NEALS co-sponsor clinical expert for people with ALS.

Do you want to know more about participating in a clinical trial? The Northeast ALS Consortium (NEALS) in conjunction with The ALS Association has established a new, centralized resource for information about amyotrophic lateral sclerosis (ALS) clinical research. An ALS clinical trial expert can be reached at (877) 458-0631 Monday through Friday between 9 a.m. and 5 p.m. Eastern Time and by e-mail at alstrials@partners.org.

For more detailed information on all these topics visit: www.alsa-or.org

To read the article online in Nature visit http://www.nature.com/nature/journal/vaop/ncurrent/full/nature10353.html
By The Numbers…

$659,275
Total dollars fundraised by Walk Teams throughout our region so far.

$41,500
Total corporate sponsorship dollars for the Walk.

$520,000
The Walk to Defeat ALS® regional fundraising goal.

327
Number of Walk Teams.

20%
The growth in the number of Walk teams from 2010 to 2011.

6,000
Estimated number of people who participated in a Walk to Defeat ALS® events in Oregon and Southwest Washington.

31%
The growth in the number of walk participants from 2010 to 2011.

10
Months until we hit Central Oregon for our first of six 2012 Walk to Defeat ALS® events!

*Totals as of October 10th, 2011

The 2011 Walk to Defeat ALS®
A year of strength, support and hope. A year of reaching new heights for families living with Lou Gehrig's Disease.

Once again, you did it. You joined a community that cares. You laced up your walking shoes and in doing so, you made an impact. This fall, thousands of people joined together in support of The ALS Association and the Walk to Defeat ALS®. Throughout the region, The Association’s six Walk events drew more people than ever before, and collectively raised more dollars than ever before. This means services, advocacy and research will continue for those living with ALS, and our local chapter looks forward to the opportunity of doing even more in the very near future.

From Central and Southern Oregon, to Eugene, Salem, Vancouver and finally, Portland – walkers joined together in support of one cause and one goal. Battling hot temperatures, windy conditions and sometimes rainy days, this community of support proved that regardless of the elements, our local chapter of The ALS Association is here to stay.

After breaking records in 2010, our local chapter set aggressive goals for growth in 2011. After all, people are being diagnosed with ALS each and every day, and the support that they need can be extreme. And no matter where people are with their ALS diagnosis, our local chapter is here for them. **With a goal of raising more than $520,000, our current fundraising shows over $700,000.** And with donations being accepted toward this effort until the end of the year, all that can be said is thank you.

There’s a reason why we love the Walk to Defeat ALS®. For those of us who are part of the Walk, we know we’re part of something bigger. The Walk gives people touched by ALS a place to fight. And the most important thing - we know that although it may feel like it sometimes, we are not alone in this journey.
When Lindsay Gray and her father, Arne, signed up for the Portland Walk to Defeat ALS®, no one could have ever imagined the success that they would have. Arne was diagnosed with ALS in October of 2010. During Arne’s professional life, he was a world-class construction lawyer at Stewart Sokol and Gray. Arne and Lindsay have raised over $70,000 for their Walk to Defeat ALS® team, Arne’s Warriors. They plan to hit $100,000 by the end of the year. Arne’s Warriors is the most successful fundraising team in our chapter’s history, and Arne is the most successful individual fundraiser.

How did they do it? They asked. They asked everyone they know, both professionally and personally. They told their story. They made it personal. And, Stewart Sokol and Gray vowed to make a $25 contribution to everyone who participated in the Walk, which ended up being over 270 members. The drive, the support and the power of this community inspires all of us. Thank you, Lindsay, Arne and Arne’s Warriors!

When they learned of their neighbor’s diagnosis of ALS, sisters Maicie and Marlie, ages 9 and 7, just had to do something. They got to work. The sisters went door-to-door throughout their neighborhood, donning a big glass jar. Their goal? To fill it up. They held a manicure and massage “spa” booth at a neighborhood block party. And on Sunday, September 25th, they Walked to Defeat ALS® with both Wilbur’s Walkers and the MSSB Support ALS teams. Maicie and Marlie raised over $200 for the cause. These girls are proof that asking for a little bit really adds up, and makes a big difference.

Members of the sketch-comedy group 100% Party Time learned of a former teacher’s diagnosis of ALS, and they just had to do something. So, they put their minds together and organized a comedy show in their former teacher’s honor. The show received great media exposure, and raised over $1,800 for the group’s Walk to Defeat ALS® team. Here, you can see Rashid Al-Robaee and Paul Richter handing over a check to Lance Christian, Executive Director of The ALS Association Oregon and SW Washington Chapter.

Well, neither could his friends and family. That’s why Paul Roeger, a member of two Portland Walk Teams, for friends Nick Ragnone and John Solomonson, decided to auction off the shaving of his ’stache. The teams, Tractors and Ragu Renegades, held a joint fundraising dinner and silent auction at their Milwaukie church. Paul’s finale helped raise over $4,000 for the teams and earned the teams some great media exposure!
WALK TO DEFEND ALS

A newsletter from The ALS Association Oregon and SW Washington Chapter
Volunteer Spotlight: The Perkins and Bassist Families

Committed to the cause – That is how we'd describe the Perkins and Bassist families. After losing Dave Perkins to ALS in 1998, the families have been influential in our chapter's growth since our chapter's inception in 2002. Once they were introduced to us, they jumped in and haven't looked back.

Through her work at Wells Fargo, Kayrin, Dave's daughter, helps recruit volunteers for all of The ALS Association's events – from the gala to the Walk, and everything in-between. Her outreach helps guarantee the success of our fundraising events. Kayrin is a resident of Portland, but helps recruit other Wells Fargo employees throughout all of Oregon and Southwest Washington.

Krystin Bassist, Kayrin's twin sister, has been an active supporter for our Dinner and Auction Gala as well, and has helped out whenever and wherever possible. From promoting the Walk to Defeat ALS® to being an overall support, we so appreciate having her in our corner.

Matt Bassist, Krystin's husband, was instrumental in our chapter's golf tournament back in the day, and has been an active member of our Board of Directors for years. Most recently, he and his company, Ashforth Pacific, helped our headquarters with a cost-savings move to a new space.

Dan Perkins, Kayrin and Krystin's brother, lives in Southern Oregon, and continually supports the Medford Walk to Defeat ALS. He fundraises through his company and even helps procure in-kind support for the event. He often travels with his family up to our Portland events whenever they can.

These are just some of the examples of how the entire Perkins/Bassist family continues a long run of involvement and chapter support since the very beginning. Matt, Kayrin, Kristin, Dan and the myriad of other family members lend a hand whenever and wherever they can.

We will never be able to list all of the things that they have done for our local chapter. For the time we've known this family, we've never heard anything but positive thinking, promotion and commitment to local families living with ALS and the goal to create a world without ALS. When this family lived with ALS, there was no local chapter. They are constantly speechless at the growth of our services and programs and the large strides we are taking to fulfill the overall mission.

Well, we are honored to have them as part of our team. THANK YOU to the Perkins and the Bassists!

Volunteers, you made it happen.

You made it great.

Not one of our events would be possible without the support and commitment of our volunteers. Thank you to all who helped with the Walk to Defeat ALS® this year. From the mailings and phone calls, to setting up day-of and cleaning up afterward, you made a difference in a big way.

If you would like to be added to our volunteer team, please email volunteer@alsa-or.org and we'll keep you up-to-date with our chapter's happenings. Coming up next? The Run Like Hell on October 23rd brought to you by Terrapin Events!

Many thanks to our 2011 Walk to Defeat ALS® volunteers!

We'd like to thank the following media outlets for covering the Walk to Defeat ALS® in some way. Whether it be event promotion, day-of coverage, or a special follow-up story, raising awareness in each community is such an important thing.

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A newsletter from The ALS Association Oregon and SW Washington Chapter
Walk to Defeat ALS® Sponsors

Ensuring all of your fundraising dollars benefit patient services, advocacy and international ground-breaking research efforts, our sponsors covered the costs of hosting the events. Thank you to the following businesses for the support of the Walk to Defeat ALS®.

Regional Sponsors:

Local business leaders support the Walk to Defeat ALS®

We thank the following business leaders for their commitment to the 2011 Walk to Defeat ALS®. These members of our 2011 Walk to Defeat ALS® Corporate Effort collectively raised over $70,000.

Trina Bandelow - Northwest Medical
Carl Cadonau - Alpenrose Dairy
Mary Beth Baker - Fred Meyer
Jim Lobdell - Portland General Electric
Cindy Miller and Brian Monoian - United Seating & Mobility
Lance Steinberg - Steinberg Aley Wealth Management
Dr. Lou Libby - The Oregon Clinic
Kristin Quinlan and Elizabeth Garvin - Certified Languages International
Angeline Adler and Management Team - CARE Medical & Rehabilitation Equipment
Doug Greenberg and Derrick Clouser - Morgan Stanley Smith Barney

Joel Sobotka - University of Portland Men's Basketball
Ann Wagner and Lisa Masat - The Standard Insurance Company
Michael O’Gara - SecureWorld Expo
Ralph Appoldt - Pride Mobility
Sam Friedenberg - Law Offices of Nay and Friedenberg
Bryan Brewis - Brewis Group
Kate Moore - Dunn Carney Allen Higgins & Tongue, LLP
Elizabeth Bowman - USI
Kimberly Lindauer - Maxim Healthcare
Jody Fasquel - Resmed
Marcy Howard - ATG Rehab
Ellen Blevins - Enterprise – Rent-A-Car of Oregon

Fundraising is possible. And it makes a big difference.

One thousand dollars. It sounds like a lot of money. That’s because it is. We'd like to give special recognition to those teams who made it to this fundraising milestone. Teams learned that once you ask, people will respond. And respond they did! Thanks to the team captains who championed this effort!

We look forward to announcing our top 5 teams in each location in our spring edition of The Voice.

Bend
Team Stern - $20,885
The Bob Squad - $6,780
The Spectators - $4,923
Stephanie’s Superstars - $3,570
Ted’s Team - $2,870
We Walk for Kay - $2,710
Team Glenn - $2,260
More for Les - $1,460
Jeff’s Jesters - $1,452
Shields - $1,180
Miles 4 Peggy - $1,135

Salem
Laurie’s Lions - $10,165
Dooie’s Booties - $5,865
Rob’s Friends and Family – 5,372
Team Wally - $4,085
Chuckie’s Entourage - $1,349.95

Eugene
Walkers in Memory of Jim Koelling - $5,025

Thank you to our 2011 Year-Round Partners: CARE Medical, Northwest Medical & Fred Meyer
Giving hope thousands of miles away

What does a sister do who lives in St. Thomas, Virgin Islands, while her sister lives with ALS in Oregon? Why, she paddles, of course.

Carrie Freyn created the idea of a paddle boarding event in her hometown of St. Thomas last year. With a decent first year turnout, Carrie, her husband, Harry, and close friends decided to make it an annual event and hosted ALS Paddle for the Cure on Saturday, September 17th of this year. Inspired by the community with her love of her sister, Sheila Watson, and her desire to change the roadmap of ALS, Carrie gathered sponsors, media support, in-kind donations of prizes and food and so much more. Putting in many hours of hard work and recruitment, she was speechless on the day of the event.

More than 100 paddlers showed up to support Carrie’s efforts and to our amazement, collectively raised over $25,000 for our chapter’s mission. Participants paddled from Hull Bay to Magen’s Bay and back.

Check out the video: http://vimeo.com/29253862 And find Paddle for the Cure on Facebook to LIKE them and see more event pictures. They plan to host the event again in 2012 and welcome anyone and everyone to join.

What a great reason to start your vacation planning now!

THANK YOU Carrie, Harry and the team of stellar volunteers and friends who made this event happen. WE are beyond words on what a sister’s love can do. Amazing actions were taken to inspire and create change.

Anita Cadonau-Huseby – fighting ALS one cookie at a time

An excerpt from Anita’s website, www. sweethopecookies.com:

It’s understandable that some people feel that finding a cure for ALS will happen when pigs fly, but what they seem to have forgotten is that pigs really can fly! No, really. I’ve seen a few airborne pigs in my own life and I’m sure you have too; those events you thought you’d never live to see happen until one day when they did.

But here’s a truism about flying pigs: If we sit around all day staring a pig down waiting for him to sprout wings that squeaker is never going to take flight but if we keep tying balloons around the pig, eventually, with enough balloons that pig is going sky high!

That’s what Sweet Hope Cookies is all about. I’m just doing what I know to add my few balloons around this one particular pig with the hope that one day, with enough balloons, those little pig hooves will lose contact with the ground and fly high.

For the day to come when ALS is curable and if not curable, treatable, we have to stop staring down the pig in resignation and do something about it. Together we need to step up to that bovine and keep tying on balloons and if we do, we might see the day come in our own lives when people with ALS will die from old age and not from ALS.

So…..what balloon are you going to tie on the pig?

Sweet Hope Cookies has raised over $7,900 for The ALS Association since February 2011.

For this, we are so grateful. And trust us, the cookies are AMAZING!

RIDE to Defeat ALS

The ALS Association

Join us on Saturday, July 14, 2012 in Mt Angel, Oregon.

Register today at www.OregonRidetoDefeatALS.org!

Help us raise $100,000 in an effort to enhance and further our mission

The Ride to Defeat ALS is a non-competitive cycling event that makes a big difference in the fight against ALS. Cyclists will 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.

Be A Sponsor – Be A Volunteer
Be A Rider – Form A Team!

To learn more about how you can be a part of this NEW event, please email ride@alsa-or.org or contact 800.681.9851
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 over 85 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.

Participants in the Ski to Defeat ALS will engage in competition with each other on most dollars raised as well as most vertical feet skied or ridden. Anyone and everyone is welcome – kids, adults, skiers, snowboarders, volunteers, supporters, people with disabilities – everyone join us for a fun-filled, inspiring day on the mountain.

There is a $75 registration fee as well as a $150 fundraising minimum per participant required.

Our staff is here to help you with everything from getting registered, finding FUNdraising ideas to recruiting friends, family, neighbors, & co-workers to join in the fun.

FIND US at the Ski Fever and Snowboard Show at the Portland Expo Center on November 4, 5, and 6.

Join Honorary Chairman, Fred Noble of CMH Heli-Skiing & Summer Adventures for this EPIC event!

Join us on Saturday, April 14, 2012 at Mt. Hood Meadows

Register today at www.skitodefeatals.org!

Help us raise $100,000 in an effort to enhance and further our mission.

– BE A SPONSOR –
– BE A VOLUNTEER –
– BE A PARTICIPANT –
– FORM A TEAM –

To learn more about how you can be a part of this NEW event, please email ski@alsa-or.org or contact 800.681.9851.

Many thanks to our current 2012 sponsors... contact us to see how you can join them in this effort.
Honing our Family Caregivers

The ALS Association, along with numerous national organizations, major corporations and community-based groups around the country, will celebrate this November as National Family Caregivers Month. During this month, we honor the millions of Americans who care for a family member or friend with an injury, consequence of old age or chronic illness, such as ALS.

The ALS Association is taking an active role in promoting and honoring ALS family caregivers, whose hard work, time and care often go unnoticed. “We recognize the monumental task and crucial role caregivers play in the lives of Americans,” stated Jane Gilbert, CEO of The National ALS Association. “Supporting people with ALS and their caregivers, along with the medical research community, is a major focus of our organization.” During November and all year long, we applaud the dedicated service caregivers provide.

Our local chapter encourage caregivers to take time and care for their own health and well-being. We encourage all caregivers to attend an ALS Family Caregiver Support group, attend an ALS Caregivers Recognition Luncheon, or simply use the chapter Respite Care Program for some time away to rest and recharge their batteries. Caregiving is an important part of managing the symptoms associated with ALS and provides an enhanced quality of life to those affected by the illness.

Take the time during the month of November and express appreciation to the family caregivers you know.

The ALS Association Respite Care Program
Giving Family Caregivers a Break

When someone is diagnosed with ALS, it is not just the person with the diagnosis that is affected. ALS often impacts the lives of family as dramatically as the person with ALS. Spouses, parents, siblings and children of people with ALS can suddenly find themselves as primary caregivers, providing full support to their loved one with ALS.

Caring for someone with ALS is hard and rewarding work! All family caregivers should be lauded for their effort and care. But, at times, family caregivers can burn the candle at both ends trying to handle the extra responsibilities of care giving while maintaining family life, employment, community responsibilities and more. To avoid depression and to recharge their batteries, caregivers need a break now and again.

The ALS Association Respite Care Program is available for the use of all people with ALS and their families residing in Oregon and SW Washington regardless of means. Up to $750 is available per family to hire non-family caregivers to give the primary family caregivers a break to rest, relax, enjoy a favorite activity, take a vacation, and recharge their batteries.

For information about accessing the Program, please contact the chapter office at 503-238-5559 ext 1., or toll free 800-681-9851 ext 1.

Walk to Defeat ALS® Sponsors continued from page 15

Bend Sponsors:
OnPoint Community Credit Union
The Old Mill District
Eberhard Dairy
Clear 101.7
The Bend Bulletin
NORCO
High Desert Produce
Ken’s Ice
Buck Makinson
Photography
Strictly Organic

Medford Sponsors:
PremierWest Bank
VIP Entertainment
Mercy Flights Explorer Post

Salem Sponsors:
Cascade Steel
Salem Hospital
Zauner Mobile Entertainment
Costco

Vancouver Sponsors:
Northwest Mobile DJ

Portland Sponsors:
Interim Healthcare
Respiriconics
DWS
Geffen Mesher
Campbell & Company
JP Morgan Asset Management
Liberty Mutual
Columbia Sportswear
USI
Vital Life Foundation
Rose City Sounds
Portland General Electric

Eugene Sponsors:
Oregon Neurology Associates
OnPoint Community Credit Union
Peace Health Medical Group
Zauner Mobile Entertainment
Mucho Gusto
Costco
Kathleen Ronning continues to connect with newly diagnosed PALS and their families. Currently, our families come from Madras, Sunriver, Prineville and Bend. Helping to serve these families through our loan closet are two staff members from NORCO, Ruth Little and Dave Hamilton. Both attended the Bend Walk to Defeat ALS® and provided loaner wheelchairs to those who needed them. NORCO also provided sponsorship for the local walk. We do appreciate their continued involvement as do those receiving their services.

Southern Oregon

PALS and their loved ones in Southern Oregon and Eugene are riding the tide of successful Walks to Defeat ALS® in September. The communities of both groups have increased in number and spirit, and Walk teams joined together to achieve fantastic results. Many participants of the Walk are active members of our support groups. Medford and Eugene support groups provide connection and validation, while speakers bring information on topics including palliative care, qualifying for Medicaid, medical marijuana, transportation options, communication technology, and financial planning.

Regional Services Coordinator Gail Gallaher continues to support PALS and their families through home visits and support groups. She provides ALS awareness and education through talks to the medical community, such as PeaceHealth care managers in Eugene, and gives interviews for radio, TV and print media. Each time an interview or story is published, we reach new PALS who are not yet aware of our services. We appreciate Anita Thomson, Charlie Wisdom and Linda Doren of Medford, and Michael and Tricia Lyton of Eugene, for their willingness to share their stories with the media.

November is National Caregiver Month, a time to recognize the essential role of family caregivers who support their loved ones living with ALS. Eugene family caregivers will be treated to dinner out at Papa’s Pizza, and Southern Oregon caregivers will gather for a luncheon at Applebee’s in Medford. We salute the commitment, compassion and generosity of all who serve their loved ones through the ALS journey. The ALS Association is dedicated to assisting family caregivers who strive daily to meet the needs and enhance the quality of life for their loved ones.

As we approach 2012, we thank our dedicated volunteers who build ramps, install home equipment and share their expertise. We also thank community partners from the Medford Eagles Lodge, Betty Johnson.

Fundraising continued from page 15

Pam’s PALS - $3,963
Nana’s Crew - $3,635
Team Dennick - $3,364
The Collier Clan Walking Toward a Cure - $1,783
Payne’s PALS Kicking ALS - $1,492
Team Tunno - $1,320
Walk and Roll in Memory of Chris Cole - $1,116.43

Vancouver
For the Love of Eric - $9,590
Jerry’s Helmsmen - $8,455
Robin’s Rockin Family - $5,544
Team Micah - $4,225
Candidora Cadets - $3,275
Brian’s Pillars of Support - $2,865
Ruth-Less Wirtanens - $2,817
Tom’s “I’d Rather be Fishing” Walkers - $2,795
Red Wigs - $3,260
Ken’s Friends - $3,630
Red Wigs - $3,260

Portland
Arne’s Warriors - $70,388
Kerry’s Kinetic Costume Crew - $2,935
Feet 2 Faith - $2,861
Jocelyn’s Jewels - $2,750
Dolby’s Devotees - $2,670
Karen’s Mitzvah Makers - $2,665
Comrades for a Cure - $2,615
For JoAnn - $2,565
Arnold’s Armada - $2,462
Peggie PALS - $2,460
Team Cindi - $2,346
Dunn Carney Defeaters - $2,339
Ted’s Heads - $2,320
Kathy’s Cuties - $2,310
Team Sugar Bear - $2,265
Team Lamvik - $2,200
The Terry Tribe - $2,133
Ward’s Walkers - $2,115
MSSB Supports ALS - $2,113.30
Pat’s Panther Pokers - $2,105
Stani’s Clan - $2,100
GO BIG! - $2,095
Arne’s Team Hope - $2,080
Wayne’s Warriors - $2,066
Susan’s Team - $2,040
Team James Morgan Read III - $1,955
Dorothy’s Dynamos - $1,920
The Standard Super-Striders - $1,910
Elinore’s Vikings - $1,900
Kathy’s Army - $1,885
Nan’s Nonconformists - $1,808
Mike’s Spirit Walkers - $1,800
Top Cat - $1,740
Seguro Big Cheese Walkers - $1,660
Gene’s Journey - $1,615
Kevin’s Posse - $1,580
Uncle Knot - $1,530
Sassy’s Soldiers - $1,445
Happy Feet - $1,425
MAC Team - $1,386
Averil’s Angels - $1,325
Joy in Montana - $1,310
Miles for Mitch - $1,305
Stu’s High Rollers - $1,295
Team Oak - $1,155
Care Medical Crusaders - $1,151.05
Lissa’s Cure Posse’ - $1,150
Team Theresa - $1,130
Team Fandango - $1,125
Patty’s Angels - $1,107
Schaffers Striders - $1,100
Fighting for Tom - $1,100
Wayne’s Warriors - $1,094
Kalan K.H. Morinaka - $1,049.99
Judy’s Cronies - $1,000
Team Helan - $1,000
Team Esmay - $1,000

*Fundraising totals are of October 10, 2011
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
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

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