Beyond the Bucket...

In the six months since the Ice Bucket Challenge soaked the nation, The ALS Association has made considerable progress in developing and executing strategies to put the incredible financial support to immediate use in the fight against amyotrophic lateral sclerosis (ALS). Last summer, 15 million people in the U.S. participated in the Ice Bucket Challenge—or roughly five percent of the population—and donated over $115 million to The ALS Association. Since that time, The Association has laid out a strategy to triple the amount it spends on research every year.

“Ice Bucket Challenge donations have enabled us to reinforce and reenergize our efforts to find treatments for this disease,” said Barbara J. Newhouse, President and CEO of The ALS Association. “We are so profoundly grateful and are committed to making the biggest impact in the fight against ALS.”

Last fall, The Association announced $21.7 million in initial commitments to ignite six projects, including four collaborative research initiatives to build understanding of the disease, target new therapies, expedite clinical trials, and make DNA and RNA sequencing data available to the entire ALS research community. This spring, The Association will be announcing additional research awards made possible by Ice Bucket Challenge donations. Currently, The Association is funding approximately 140 active projects globally. Projects are milestone driven, which enables The Association to redirect dollars when the science demonstrates that one approach is not feasible, and another is more promising.

“We’ve received triple the amount of applications for research funding than we did last year,” said Newhouse, “a positive sign that the Ice Bucket Challenge has energized the research community.” At the end of January 2015, The Association launched a Drug Discovery call to support academic and industry partners to develop novel treatment approaches. Funding will support all aspects of drug discovery up until the clinical trials stage.

“It can take upwards of $1-2 billion to develop one effective treatment, so it’s critical that we continue the momentum around ALS that started with last summer’s Ice Bucket Challenge,” said Newhouse.

Right here in Oregon and SW Washington, the local chapter of The ALS Association has enhanced its Care Services programs by increasing participation in its In-Home Caregiving Program, expanding its Assistive Technology Support Program, and growing their supports for children who have a parent or grandparent living with ALS. In partnership with the National ALS Association, the local chapter is also cementing its commitment to ALS research by gifting additional dollars, outside of what the chapter gives each quarter. The chapter is excited to share more details in the near future.

“Our chapter is thrilled to increase its capacity and its care services to continue to meet the needs of local families living with ALS. Last year, alone, our qualified staff of 10 professionals provided hands-on support and tangible benefits to 406 people living with ALS along with their family members, friends, neighbors and co-workers,” said Lance Christian, Executive Director.

CHANGE OF ADDRESS:
If you’ve recently moved, give us a call or send us an email and let us know your new address. If you no longer want to receive this newsletter or other Chapter information, please help us save on costs and let us know. Thank you!
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:

- Maureen Stoner
- Janet “Jan” Simmons
- Ken Feldhaus
- Matson “Matt” Haug
- Mike Carnahan
- Glenna Ashley
- Glenn Blair
- Wanda “Sue” Case
- Olive Cotton
- JoAnne Cummings
- Catherine “Cathy” Curths
- Donna DeGuire
- Florence Delaney
- Jeff Farber
- Bill Gabel
- Babette “Babs” Gray
- Leah Hammer
- Robert “Bob” Hawkins
- Robin Hill
- Richard “Rick” Hirst
- John Horton
- Mindy Kallunki-Hill
- Frederick “Fred” Nelligan
- Shirley Oxidine
- Cindi Patterson-Nichols
- Mary Jo Picascia
- Richard “Dick” Rawie
- David “Dave” Rux
- Dorothy Sandall
- Terry Shields
- Kathryn “Katie” Smith
- Paul Speck
- Laurie Speight
- Edna Stanley
- Dennis Stevens
- Douglas Strutz
- Gregory Tethorster
- Jocelyn Tuthill

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

The ALS Association Oregon and SW Washington Chapter has made every effort to ensure the memorials, tributes, and donations are properly recognized and correctly spelled. We apologize for any errors and ask you to call us at 1-800-681-9851 ext 103 with corrections so our records can be changed and updated.
We Are Hiring!

To view full job descriptions, please visit the front page of our website at www.alsa-or.org.

We have an open position for our **Assistive Technology Services Coordinator**. Resume and cover letter to be emailed to careservices@alsa-or.org.
No phone calls, please.

We have an open position for our **Marketing and Communications Coordinator**. Resume and cover letter to be emailed to AubreyMcCauley@alsa-or.org.
No phone calls, please.

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**In Memory of Our PALS**
October 1, 2014 – February 28, 2015

Glenn Asbury  
Glenna Ashley  
Daniel “Dan” Berry  
Georgette Brown  
Kenneth Byrne  
Wanda “Sue” Case  
Dolores Cassinelli  
Virgil Crock  
JoAnne Cummings  
Dennis Decker  
Elizabeth “Betsy” Dial Mills  
Don Eckles  
Michael Eichman  
Clark Elliott  
Michael Mike” Gilbert  
Emma “Jean” Glaus  
Susan Goetz  
Judy Grossbard  
Ray Hancock  
Leslie “Les” Harvey  
Robin Hill  
Richard “Rick” Hirst  
Lynn Holmes  
John Horton  
Donald Hulick  
Jon Kimmett  
Daniel Kurth  
James “Jim” Lopez  
Herbert “Scott” McCartney  
Kevin McGee  
Joan Mcllroy  
Tom Miller  
Frederick “Fred” Nelligan  
Robert “Bob” Newburn  
Kevin Orrick  
Shirley Oxidine  
Sherman Radtke  
Ricardo “Rick” Ramento  
Ronald Reddekopp  
Daryl Ross  
David “Dave” Rux  
Bernard “Bernie” Saalfeld  
Kathryn “Katie” Smith  
Kum Smith  
Jacqueline Sorrells  
Erika Velez  
Frances Vermeire  
Deborah Vose  
Phil Wilcox  
Alvin Youngs

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

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**OUR ESTEEMED ADVISORY BOARD MEMBERS**

Marcia Bagnall  
Chemeketa Sm. Business Development Center

Jon Buccola  
Greenpoint Technologies

Carl Cadonau Jr.  
Alpenrose Dairy

Mark Edlen  
Gerd영 Edlen Development

Ken Fink  
Paralyzed Veterans of America

Douglas Greenberg  
Morgan Stanley

April Hughes-Sanders  
Wells Fargo

James Lobdell  
Portland General Electric

Betsy McCool  
The Bend Bulletin

Joy Olson  
Southern Oregon Humane Society

Kristin Quinlan  
Certified Languages International

Tobias Read  
Oregon State Rep. for House District 27

Lance Steinberg  
Steinberg Investment Group

David Underriner  
Providence Health & Services

Anne Weaver  
Elephants Delicatessen

Kenneth Willett  
Liaison Healthcare Informatics

**THANK YOU TO OUR 2015 YEAR-ROUND PARTNERS**

[Logo images for various sponsors]

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Thank you to our 2015 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, JGP Wealth Management, Wells Fargo and Numotion.
In Fall of 2014, we hosted our first ever Family Fun Day at the zoo. Adults learned about developmental stages of children and communication strategies around discussing ALS. The children were busy getting up close and personal and learning about some furry friends. Everyone came together for a tasty picnic and then went off to enjoy the rest of the day at the zoo. We are looking forward to more family fun in 2015 so stay tuned!

**Update from Mary Rebar - Willamette Valley**

A new support group launched in Salem! The Caregiver Support Group meets on the second Tuesday of the month, from 4-5:30pm, at the Broadway Commons Coffee Shop on the second floor. A local Surviving Spouse shall attend the April meeting to discuss her family’s experience with Veteran’s Administration ALS Clinic and the variety of programs available to Veterans. Please contact Mary for more information on joining the group!

The people living with ALS in Lincoln and Coos Counties received home visits. Mary enjoyed traveling the Coast, visiting with families and the beautiful ocean.

The ALS Loan Closet at the NuMotion Office in Springfield experienced spring cleaning by Teri Humphrey, Operation Manager, and Larry Humphrey, Warehouse Technician, assisted Mary for a day of cleaning and organizing the large variety of durable medical equipment available for people living with ALS. The Loan Closet received an infusion of brand new equipment; including transport chairs, manual wheelchairs, toilet safety rails and shower benches.

**Update from Lance, Karen and Rachelle - Portland/NW Oregon/ SW Washington**

In the Portland Metro and SW Washington area, care services staff Lance Christian, Karen Galloway and Rachelle Preston continue to serve individuals living with ALS and their families through home visits, support groups and multidisciplinary clinic participation at Providence, Kaiser Permanente and the Veterans Administration. They engage in numerous home visits to provide initial support to newly diagnosed families as well as ongoing care to families thorough the progression of the disease.

As always, support groups in Vancouver, NE Portland and Beaverton were well attended. In addition to the opportunities for members of our ALS community to come together to share information, experiences and enjoy support valuable education is offered at the groups. Recent education programs featured speaker Donna Delikat, from Senior Health Insurance Benefit Assistance (SHIBA) Insurance Division who provided information on Medicare open enrollment, Sam Friedenberg, J.D. came to discuss estate and Medicaid planning, Dale Gross and Dave Bearson and came to share what to consider when remodeling a home for accessibility and our own Shana Tognazzini, SLP who led an engaging dialogue about assistive technology. We also had fantastic holiday celebrations where we had the opportunity to share some food and stories with one another.

**Update from Lance, Karen and Rachelle - Portland/NW Oregon/ SW Washington**

The Center’s Dr. Viviane Ugalde, Physical Medicine physician, leads the Clinic which is a collaborative effort with physicians and therapists from both St. Charles and Bend Memorial Clinic. The next ALS Clinic will be May 8th 2015 at The Center. If you are interested in attending please contact Rachelle Curley, Clinic Coordinator at 541-312-3502 or rcurley@thecenteroregon.com.

The Central Oregon ALS Support group meets the second Wednesday of each month at St. Charles Hospital in Bend from 11:30 – 12:30pm. Friends, family, caregivers and those living with ALS are all welcome to join this supportive group. Speakers are often invited to provide education on various resources and supports in the area. Polly Evans from the Partners in Care Transition program joined us in December to describe the life review and legacy projects that Partners in Care volunteers have been trained to offer to the community. In January, we were fortunate to have Karin Morris, City of Bend Accessibility manager who described her involvement and advocacy for not only curb ramps, but sidewalk maintenance and snow removal. Most importantly that day we learned about Bend’s Good Samaritan program that aids seniors and those with limited mobility assistance with snow removal (for more information contact the city volunteer coordinator at 541-388-5579). February brought Vivien O’Connor to our group who is the Bend and S. County coordinator with Volunteers in Action. Volunteers in Action offers assistance with installment of ramps and grab bars, short term respite, grocery shopping, and various “handy man” assistance.

Think you might need some equipment for your bathroom? In Central Oregon, we partner with Norco to offer a Central Oregon ALS Loan closet. The closet has important equipment such as power chairs, transport wheelchairs, shower chairs, commodes and lifts. Big thanks to Norco’s David Hamilton and Chris Lathrop for delivering and picking up donated equipment. We also want to thank JoAnne Bernt for her volunteer efforts keeping the closet organized!

**Update from Gail Gallaher - Southern Oregon**

In addition to assisting with the new ALS clinic, Regional Services Coordinator Gail Gallaher has continued her outreach to home health and outpatient programs that provide therapies and support to PALS. She gave presentations to Providence Case Managers, VA Home Based Primary Care, and Asante Rehab Services. Gail visits PALS at home, coordinates the medical equipment loan closet, and leads support groups. She is available to speak to community organizations, service clubs, and the media to raise awareness about ALS and chapter services.

The Medford support group meets on the third Thursday of each month and has welcomed many new members. Recent speakers and topics include Joanne Kliejunas on getting affairs in order; Diana Spade on Oregon’s Death With Dignity Law; Kristi Scott on respiratory care; and our own Karen Galloway on chapter care services. The Family
Caregiver support group meets on the second Tuesday of the month and offers a place for shared ideas, strategies and comfort to those caring for loved ones of PALS.

Throughout the month of January, our community partners at the Medford Eagles Lodge hosted a series of fund raising events that replenished the account shared with local PALS for out-of-pocket expenses. Each year, Betty Johnson and Rae Eatherton coordinate these events in memory of a fellow Eagle member living with ALS. Funds pay for vehicle, appliance and computer repairs, phones and medical equipment, and travel expenses. We thank Betty and Rae for their steadfast dedication, and for the monthly luncheon they host at the lodge.

Thanks to Laurie Sanderson at NuMotion for maintaining our medical equipment loan closet. Continued thanks to volunteers Claire Shields for baking treats for meetings, Larry Johnson for vehicle repairs, Betty Lou Lore for storing ramp materials, and Keith McCooshum for building ramps for people living with ALS. And finally, thanks to Right at Home Care Services for providing excellent care through our partnership in our In-Home Caregiving Program.

Resources for Children and Teens

When a family member has been diagnosed with ALS, children and teens have many questions and concerns about the person they know and love. In an effort to support the whole family adapting to and living with ALS, our chapter offers resources and supports for families with children and teens.

We partner with The Dougy Center for Grieving Children and Families and their Pathways Program. This free bi-monthly peer support group is designed respectfully for children, teens, parent or adult caregivers and adults with terminal illness. Additionally, the Chapter has educational materials for parents on how to help children and teens cope with ALS; and education for children and teens. Each Fall, the Chapter offers a Family Fun Day; last year’s event at the Portland Zoo was a very fun time and great success! Plans are underway for our 2015 Family Fun Day.

If you would like more information about our Resources for Children and Teens, contact Karen Galloway, Care Services Director at karengalloway@alsa-or.org or 800.681.9851 ext 100.

Care Services

By The Numbers in 2014

Our chapter provided hands-on support through our care services and programs to 406 families in 2014. Here are just a sampling of our care services and their impact on the local community:

Medical Equipment Loan Program
- Served 180 families with 488 requests. (each request may have multiple items.)
- Restocked the loan closets with manual wheelchairs, transport chairs, shower chairs with backs, raised toilet seats, toilet rails, drop arm commodes, sliding transfer benches, and more.

Assistive Technology Program
- Supported over 150 families in being able to communicate via our dedicated AAC position.
- Provided AAC specialist to 64 clinic days.
- Restocked our AAC loan closet with 5 tablets, 3 Tobii eyegaze devices, 20 Chattervoxes, adaptive mice, numerous switches, switch adapted door bells, and more.

Home Visits
- 425 documented home visits from our Care Services Staff.

Monthly Support Groups
- 132 Monthly Support Groups offered in 11 locations.

Caregiver Support Programs
- 48 families accessed our Respite Care Program.
- Over 9,000 hours of paid caregiving was provided through our In-Home Caregiving Program.

Resources for children and teens
- Hosted 100 people at our inaugural Family Fun Day at the Oregon Zoo

New Clinic in Southern Oregon

Southern Oregon is very pleased to announce a new multidisciplinary ALS clinic for our region under the leadership of neurologist Eric Lee. Dr. Lee joined the Asante Physician Partners with the goal of creating a clinic for local PALS to provide the same comprehensive care and support they have found in Portland and San Francisco ALS clinics. The first Southern Oregon clinic was held on March 2, 2015 at Asante Three Rivers Outpatient Rehab Services in Grants Pass. Dr. Lee and his excellent team have the full support of the ALS Association Oregon & SW Washington Chapter. Monthly clinics are planned and Dr. Lee welcomes new patients to his practice in Grants Pass and Medford.
A Note of Encouragement from One Caregiver to Others:

Nick and Cheryl at our Portland Support Group Holiday Party in 2012

My husband, Nick, was diagnosed with ALS in 2007. We are into our 8th year living with this diagnosis. I kept hearing “you need a break”, but when you are married 43 years, you think not really, this is our life and we are a team. Well, this past November, our daughters gave me a gift I did not realize that I needed. 7 days away. I thought to myself, “How can I leave Nick in his chair and go out having fun?!” Nick smiled upon the news and said, “go, please.”

During my time away, I was able to sleep in, have coffee out in the warm sun, enjoy my feet on warm sand, spend some time shopping, eat out at various restaurants, and more. I called home to check in when I could. All was taken care of.

Caregiving for someone you love is a blessing and I thank God he made me strong to do this. I know Nick would do the same for me. But everyone needs a break. No one can do it full-time, all the time.

Going away, giving myself respite, allowed me have time to think about and realize all of the gifts that this journey have given us. It gave me time to just be. I came back stronger, rested, relaxed and energized to continue to be the best caregiver to my wonderful husband.

I would encourage all caregivers to try and do the same. Not easy, but very rewarding.

With love, Cheryl Ragnone

In-Home Caregiving Support

We know that everyday tasks become increasing difficult throughout an ALS journey. Tasks that used to be automatic like taking a shower and getting dressed in the morning now take hours of the day. A trained caregiver through an agency can be a great benefit to those living with ALS and their families to help with all sorts of tasks including personal care, light housekeeping and companionship.

Our In-Home Caregiving program is here to help! We offer six hours per week of caregiving support for qualifying people living with ALS and their families. Our In-Home Caregiving program continues to expand with new agency partners and participants, maybe this is for you!

Who qualifies?
This program is for those with ALS who live in their home and qualify for no other federal or state assistance.

How do I apply?
Please reach out to your local Regional Services Coordinator or email homecare@alsa-or.org for additional information.

Is there a cost to this program?
No, these six hours of care are free of charge. Some families do choose to purchase additional hours at their discretion.

Is there a waiting list?
Yes, this program serves a limited number of participants and has a first come, first served waiting list.

What can caregivers help with?
- Range of motion exercises
- Laundry, dishes, and meal preparations
- Helping with feeding and managing PEG tubes
- Bathing, dressing, grooming
- AND much more!

We asked some of our participants - What does having access to this program mean to you?

“This provides me with help to keep up with housework and it also gives my husband additional range of motion twice a week and a bath.”

“Our caregiving agency is excellent and thus not cheap. I was stretched to afford it so had to go into my retirement funds - the help received from the ALS Association eased my stress considerably.”

“It lets me go to work without fear or guilt. The caregivers are compassionate, skilled and reliable.”
Thank you to our 2015 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, JGP Wealth Management, Wells Fargo and Numotion

Registration is now open for the 2015 Walk to Defeat ALS®! We’re excited for another fun and successful Walk season. Grab your friends, family, coworkers, etc. and form a team today!

Central Oregon Walk to Defeat ALS®
Saturday, September 12, Riverbend Park, Bend, OR
www.CentralOregonWalktoDefeatALS.org
Contact Rebecca Pace for more information.

Southern Oregon Walk to Defeat ALS®
Sunday, September 13, Bear Creek Park, Medford, OR
www.SouthernOregonWalktoDefeatALS.org
Contact Rebecca Pace for more information.

State Capitol Walk to Defeat ALS®
Saturday, September 19, Riverfront Park, Salem, OR
www.StateCapitolWalktoDefeatALS.org
Contact Julia Mayfield for more information.

Willamette Valley Walk to Defeat ALS®
Sunday, September 20, Lively Park, Springfield, OR
www.WillametteValleyWalktoDefeatALS.org
Contact Julia Mayfield for more information.

Portland Metro Walk to Defeat ALS®
Sunday, September 27, World Trade Center, Portland, OR
www.PortlandMetroWalktoDefeatALS.org
Contact Rebecca Pace for more information.

SW Washington Walk to Defeat ALS®
Saturday, October 3, Esther Short Park, Vancouver, WA
www.SWWashingtonWalktoDefeatALS.org
Contact Julia Mayfield for more information.

Cheers to our TOP fundraisers from the 2014 Walk to Defeat ALS® Season!

Central Oregon Walk to Defeat ALS®
Top Team - Team Stern $29,317
Top Individual - Eberhard Dairy Employees $8,834

Southern Oregon Walk to Defeat ALS®
Top Team - SWIFTSURE $17,050
Top Individual - Colton Allen $6,225

State Capitol Walk to Defeat ALS®
Top Team - Laurie’s Lions $10,110
Top Individual - Joseph Speight $6,110

Willamette Valley Walk to Defeat ALS®
Top Team - Remembering Jim Koelling $7,584
Top Individual - John Koelling $7,314

SW Washington Walk to Defeat ALS®
Top Team - Ran’s Fans Walking for Mike’s Marauders $13,235
Top Individual - Art Lothrop $9,060

Portland Metro Walk to Defeat ALS®
Top Team - CullyKins $27,594
Top Individual - Lindsay Gray $20,129

How To Raise $1,000 In Ten Days
Really, It’s Easy

1. Sponsor yourself for $50
2. Ask 2 of your family members to sponsor you for $50
3. Ask 10 friends to contribute $20
4. Ask 5 co-workers to contribute $20
5. Ask 5 neighbors to contribute $20
6. Ask 10 people from your place of worship to contribute $10
7. Ask your boss for a company contribution of $50 (or better yet find out if your company will match what you raise!)
8. Ask 5 businesses or companies that your business works with to sponsor you for $40
9. Ask 4 businesses you frequent to contribute $25
10. Share your success with your friends and family!

Rebecca and Julia are here to help with everything from registration to teambuilding to fundraising and more. Give them a shout today! Rebecca Pace can be reached at 800-681-9851 ext 106 or RebeccaPace@alsa-or.org
Julia Mayfield can be reached at 800-681-9851 ext 107 or JuliaMayfield@alsa-or.org
Check Out Our 2015 Walk T-Shirt!

Want to help us blow our goals out of the water?
Go above and beyond . . . and be rewarded!

Raise $75 or more, and you will be eligible to receive the 2015 Walk to Defeat ALS® T-shirt on Walk Day!

HOT TIP
Meeting the T-shirt Minimum in Three EASY Steps:
1. Donate $25 yourself.
2. Ask 2 friends to match your self-donation.
3. You’re there!

JOIN OUR EXTRA MILE CLUB

In 2014, the 60 members of the Extra Mile Club raised over $210,000. Be part of this exciting club!
Take the extra step and pledge to raise $1,000 as an individual fundraiser by Friday, August 28th!

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

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

* To receive the Extra Mile Club benefits, your pledge of $1,000 or more as an individual must be fulfilled and all money turned in to The ALS Association no later than Friday, August 28th. Gift may be picked up at the EMC table on Walk Day.

* In order to be eligible for the Extra Mile Club, Walkers must be registered online and select “yes” to be part of the program during registration. If you missed this question, no worries! Contact your Walk Coordinator to get enrolled in this awesome club.
Ride to Defeat ALS
Presented by Alpenrose Dairy

It’s almost that time of year again - five exciting and scenic routes, delicious berry turnovers and strawberry shortcake, and the rolling hills of Marion County are calling your name. We hope you can once again join us for the Ride to Defeat ALS presented by Alpenrose Dairy on Saturday, July 18th!

Our five fully-supported routes are one of a kind. Register for our Century Ride, Metric Century Ride, 50 Mile Ride, and 25 Mile Ride, or the Family Fun Ride around Mt. Angel.

So, what are you waiting for? Save the Date for Saturday, July 18th and register today! Be sure to take advantage of our Earlybird Registration Fees through May 1st, and tell your friends and family to do the same. Here are the basics about the Ride to Defeat ALS:

- Saturday, July 18th on the roads around Mt. Angel, Oregon
- Family Fun Ride, 25 mile, 50 mile, Metric Century (62 miles) or Century (100 miles) Rides
- $35 Registration Fee for Adults ($25 Earlybird Registration before May 1st)
- $15 Registration Fee for Children ($10 Earlybird Registration before May 1st)
- $150 Fundraising Minimum for People Ages 11 and Older
- Go above and beyond: Raise $250 for a pair of Ride to Defeat ALS cycling socks, $500 for a 2015 Ride to Defeat ALS VIP Jersey, or $1000 for them BOTH!

NEW THIS YEAR! We will be giving away a high-end BMC road bike to one lucky cyclist who fundraises $1,500 or more!

Because of your support in 2014, we were able to raise $179,000. One hundred and seventy nine thousand dollars to help provide care services, fund public policy efforts, and research for creating a world without ALS. We know you can help us reach our exciting goal of $200,000 this year. Help us go above and beyond in this fight, and sign up today! www.OregonRidetoDefeatALS.org

For more information, contact Rebecca Pace at ride@alsa-or.org or 800-681-9851 ext 106.
Tell us where to give!

With Community Rewards, you help decide which organizations Fred Meyer supports with $2.6 million in donations annually—and that’s on top of earning Rewards Points & Fuel Points!

To add your support to The ALS Association Oregon & SW Washington Chapter, sign up at fredmeyer.com/communityrewards & choose organization #84544.

Your Gift, Your Way

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

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

Below are individuals, corporations, and foundations who are dedicated to the fight against ALS. All have demonstrated **hope, strength, determination, and courage**... and are inspirations to each and every person in our community that is affected by this disease. Thank you for being our **CIRCLE OF HOPE**.

**Our Heroes: $300,000+**
- Mr. Jon Buccola
- Alpenrose Dairy

**Our Inspiration: $100,000 - $299,999**
- The Kenneth and Jane S. Libby Foundation
- Trina and Jeff Bandelow

**Our Courage: $25,000 - $99,999**
- Northwest Medical
- Barbara and John Deeming
- Jocelyn and Dr. Lou Libby
- Barbara and John Seibert

**Our Determination: $15,000 - $24,999**
- D随和 with whom we are no longer with us.

For the purposes of this listing, only monetary lifetime giving has been listed as of December 31, 2014. Names in italics denote those generous individuals who are no longer with us.

Thank you to our 2015 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, JGP Wealth Management, Wells Fargo and Numotion.
Volunteer Spotlight

Our Annual ALS Dinner & Auction Gala is one of the most special nights of the year. Part of what makes the event so special is our silent auction, made up of beautiful artwork, unique items, exciting experiences, culinary adventures, and so much more. What makes our silent auction so remarkable? Aside from the generous auction item donors, it is our incredible Auction Procurement Committee who produce a wonderful marketplace of items to feature on this special night.

Our Auction Procurement Committee is made up of a group of dedicated volunteers, headed by Auction Procurement Chair Shelley Lowenstein, who spend months procuring donations from a variety of businesses and supporters. They spend time researching, making calls, sending emails, doing pick-ups, to ensure our auction has a unique array of items that will appeal to all sorts of tastes. Whether it is a gift certificate to a trendy restaurant downtown, or a beautiful print by a local photographer, to a wine tasting experience, there is truly something for everyone.

We are thrilled to feature our Auction Procurement Committee in our Volunteer Spotlight this spring. Shelley Lowenstein, Julie Swearingen, Lindsey Salzer, Cindy Carnahan, Kristin Erickson, Bill Muller, and Monika Lewis – we couldn’t have done this without you. Thank you for your hard work, your valiant efforts, and most of all, your most valuable volunteer commitment – your time.

We truly cannot thank you enough.

If you are interested in more information about joining our 2016 Auction Procurement Committee, contact Julia Mayfield at JuliaMayfield@alsa-or.org or 800-681-9851 ext 107.

Upcoming Volunteer Opportunities!

We have many exciting volunteer opportunities coming up in the next couple of months. Whether you’re a cyclist, enjoy representing our organization, or love the Walk, we have a job for you! Find below a complete list of ways you can help. For more information contact Rebecca Pace by phone at 800-681-9851 ext 106 or by email at volunteer@alsa-or.org.

**ALS Research Symposium**
Saturday, May 16
Red Lion Hotel on the River

**Ride to Defeat ALS**
Saturday, July 18
Mt. Angel Festhalle, Mt. Angel, OR

**Central Oregon Walk to Defeat ALS®**
Saturday, September 12
Riverbend Park, Bend, OR

**Southern Oregon Walk to Defeat ALS®**
Sunday, September 13
Bear Creek Park, Medford, OR

**State Capitol Walk to Defeat ALS®**
Saturday, September 19
Riverfront Park, Salem, OR

**Willamette Valley Walk to Defeat ALS®**
Sunday, September 20
Lively Park, Springfield, OR

**Portland Metro Walk to Defeat ALS®**
Sunday, September 27
World Trade Center, Portland, OR

**SW Washington Walk to Defeat ALS®**
Saturday, October 3
Esther Short Park, Vancouver, WA
Whole Exome Sequencing Reveals New ALS Gene

A gene that may cause more than one percent of all ALS cases has been discovered through “whole exome sequencing” of more than 1,500 people with ALS. The gene, called TBK1, plays a role in clearance of damaged cell components, strengthening the belief that this clearance process, called autophagy, may play a central part in the ALS disease process. The study was published in the journal Science.

The study, led by David Goldstein, Ph.D., of Columbia University, drew on the combined efforts over two dozen laboratories in six countries, highlighting the global and collaborative nature of ALS research today. The “exome,” or entire coding region of DNA, was sequenced from 2,874 people with ALS and 6,405 unaffected control individuals. Whole exome sequencing has emerged as a significant advance in gene hunting in the past decade.

“This important discovery points strongly at the autophagy pathway, which has also been implicated from other studies,” said ALS Association Chief Scientist Lucie Bruijn, Ph.D., M.B.A. “That will help us focus our efforts on understanding that process as a possible target for therapy.”

Mutations in TBK1 were found in about 1.5 percent of ALS cases and only 0.2 percent of controls. The protein encoded by TBK1 interacts with two other proteins implicated in ALS, optineurin and p62, which also have roles in the autophagy pathway.

“We are strongly encouraged by this discovery,” Dr. Bruijn said. “Finding a new gene is always important, as it provides new ideas about the ALS disease process. The fact that TBK1 interacts with other known ALS genes gives us confidence that this pathway is likely to be critical in ALS and suggests that therapeutic strategies targeting this pathway should be pursued.”

New Disease Model Highlights Astrocyte Contribution to ALS

A significant new model of ALS has been created that will help elucidate the contribution of cells called astrocytes to the disease. Astrocytes are support cells for neurons within the central nervous system and have been previously implicated in the ALS disease process.

Researchers led by Association-funded researcher Su-Chun Zhang, M.D., Ph.D., of the University of Wisconsin at Madison, implanted cells called neural progenitors into the spinal cords of adult mice. The neural progenitors were derived from either human embryonic stem cells or induced pluripotent stem cells (iPS cells), which are derived from human skin tissue. Consistent with previous studies of transplanted neural progenitors, the cells developed into astrocytes and migrated away from the site of implantation. Over time, the astrocytes replaced the mouse’s own astrocytes, integrating into the nervous system without apparent untoward effect.

When the implanted neural progenitors were derived from people with ALS, the astrocytes also migrated and integrated into the mouse nervous system but caused motor deficits similar to those seen in genetically created ALS mouse models.

“This new model should allow us to rapidly explore the unique contribution of astrocytes to the ALS disease process,” commented Lucie Bruijn, Ph.D., MBA, Chief Scientist for The ALS Association. “We may also be able to test astrocyte-related therapies in this model, including delivery of growth factors or other molecules supplied by the astrocytes themselves. The discovery that astrocytes derived from people with ALS resulted in motor neuron deficits in these mouse models is significant and should be carefully considered as we move to developing approaches using a patient’s own cells for transplantation.”

The study was published in the Journal of Clinical Investigation.

SAVE THE DATE!

Our 2015 ALS Research Symposium will be held

Saturday May 16

at the Red Lion Hotel on the River in Jantzen Beach from 1 – 4 pm.

Featured this year, Kim Goslin, M.D. Ph.D., Medical Director of the Providence ALS Center and Joe Beckman, Ph.D., Principal Investigator and Ava Helen Pauling Chair for the Linus Pauling Institute, Director of the Environmental Health Sciences Center and Distinguished Professor with the Department of Biochemistry and Biophysics Oregon State University. Watch your inbox and mailbox for details and registration information. You will not want to miss this year’s Symposium!
PROGRESS BY THE BUCKETFUL

FROM ONE TO MILLIONS

It all started on July 15, 2014 with golfer Chris Kennedy and quickly spread from his social network to others living with ALS. Within six weeks, more than 2.5 million people participated and/or donated, including many celebrities worldwide.

$115,000,000

Raised nationally

$220 MILLION

Raised worldwide

The ALS Association and its 38 chapters nationwide reached an all-time donation record.

MORE FUNDS = more progress where it matters most

RESEARCH

Tripling our annual research spending
Funding major new collaborative projects
Ensuring promising research remains funded

PUBLIC POLICY

Speeding up treatments to patients
Encouraging companies to invest in ALS research
Breaking down barriers for drug approval

CARE

Increasing grants to Certified Centers of Excellence
Expanding access via alternatives of care delivery
Broadening scope of programs and services

WHY IT MATTERS: the chilling facts about ALS

$1 Billion+
cost of bringing one new drug to market

5000+
people are diagnosed each year

2–5 Years
average life expectancy

2x
Military Veterans are twice as likely to get ALS

Why stop now?
You have a shot at changing the world, in a way, and there’s no reason to stop having fun... not only have fun, but you’re creating awareness for a disease that has something special that’s happening. God-willing, a cure could come.”

—Pat Quinn

What is ALS?

Amyotrophic Lateral Sclerosis
ALS is a disease that attacks the nerve cells in the brain and spinal cord that control voluntary muscle movement. It robs you of your ability to walk, talk, and eventually breathe, and it’s always fatal.
Dear ALS Advocate:

In 2014, the ALS Ice Bucket Challenge forever changed the fight against the disease. Who will ever forget the images we saw each day last summer of people being soaked with ice water all in the name of ALS? Everywhere you looked, people were talking about ALS! Everyone from Oprah to Derek Jeter, Leonardo DiCaprio to Taylor Swift and everyone in between all over the world took part. The Ice Bucket Challenge was one of the year’s top five searched terms on Google and was one of the most trending topics on Facebook and Twitter. It quite simply was everywhere.

People everywhere joined the fight – our fight – against this horrific disease thanks to three people with ALS who helped make the challenge go viral because they wanted to make a difference. And they did!

The success of the Ice Bucket Challenge also presents us with new opportunities to make a difference in Washington, DC. That’s because the level of awareness of ALS that exists on Capitol Hill today has never been greater. And we must seize on this increased visibility in order to generate continued funding for ALS research and support for policies that can enhance the lives of people with ALS.

While the Ice Bucket Challenge raised significant funding for ALS, more must be done to find a treatment. The United States government remains the single largest source of funding for ALS research and health care in the world. And we need to make sure Members of Congress know that the fight against ALS is not over because of the success of the Ice Bucket Challenge.

It also is vital that we take advantage of this increased visibility because we still face significant obstacles in Washington. Partisan politics and tight budgets continue to present challenges to our success. Moreover, some of our most influential champions have retired from Congress or recently passed away. As a result, we need to identify new champions and strengthen our relationships with existing supporters in addition to educating the more than 70 newly elected Members of Congress who won their elections last November. Yes, we have more work to do!

Therefore, The ALS Association is pleased to host the National ALS Advocacy Day and Public Policy Conference in Washington, DC May 10-12, 2015.

This is our opportunity to share the ALS story, to let Members of Congress know the true nature of the disease and why more must be done as soon as possible.

Representing the Oregon and SW Washington Chapter of The ALS Association will be Rachelle Preston, Care Services Coordinator, Rebecca Pace, Development Manager, and the Allen Family from Talent, Oregon. We encourage others to attend with our group.

If you would like to attend or plan on attending this conference, please contact:

Lance Christian, Executive Director
LanceChristian@alsa-or.org
800.681.9851 ext 101.

Thank you to our 2015 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, JGP Wealth Management, Wells Fargo and Namotion
The Voice
BRINGING YOU THE LATEST NEWS ON FIGHTING LOU GEHRIG’S DISEASE IN OREGON AND SW WASHINGTON

MONTHLY SUPPORT GROUP SCHEDULE

SOUTHWEST WASHINGTON REGION
Second Wednesday of every month
3:00pm - 4:30 pm
St. Luke’s Episcopal Church
426 E Fourth Plain Blvd.
Vancouver, Washington 98663

For more information and directions contact:
Karen Galloway at 503-238-5559 ext 100.

PORTLAND METRO REGION
Eastside Group
First Wednesday of every month
3:00pm - 4:30 pm
Providence Portland Medical Center
Social Room, First Floor
4805 NE Glisan St
Portland, Oregon 97213

For more information and directions contact:
Lance Christian, LMSW at 503-238-5559 ext. 101
or Clare Cross RN at 503-215-8580.

Westside Group
Third Wednesday of every month
3:00pm - 4:30 pm
Beaverton City Library
Cathy Stanton Conference Room
12375 SW 5th St
Beaverton, OR 97005

For more information and directions contact:
Rachelle Preston, MSW at 503-238-5559 ext. 110.

Family Caregivers Group
(Note: this group is for family caregivers only.
People with ALS do not attend this group).
Third Thursday of every month
1:00pm - 2:30pm
Legacy Meridian Park Hospital
Health Education Center Room 106
19300 SW 65th Ave.
Tualatin, Oregon 97062

For more information and directions contact:
Rachelle Preston, MSW at 503-238-5559 ext. 110.

STATE CAPITOL REGION
Third Wednesday of every month
3:00pm - 4:30pm
Salem Hospital Community Health Education Center
(CHEC)
930 Oak Street E, Salem, OR 97301
1st Floor, Building D, Room CHEC 1
Salem, Oregon
Drop off area at the front of the building,
covered hospital parking off Capitol Street NE.

For more information and directions contact:
Mary Rebar at 541-990-1246.

WILLAMETTE VALLEY REGION
Second Wednesday of every month
3:00 pm - 4:30 pm
Hilyard Community Center
2580 Hilyard Street
Eugene, Oregon

For more information and directions contact:
Mary Rebar at 541-990-1246.

SOUTHERN OREGON REGION
Third Thursday of every month
2:00pm - 3:30pm
Smullin Center
2825 E Barnett Rd
Medford, Oregon 97504

Family Caregivers Group
(Note: this group is for family caregivers only.
People with ALS do not attend this group).
Second Tuesday of every month
1:00pm - 2:30pm
Smullin Center
2825 E Barnett Rd
Medford, Oregon 97504

For more information and directions contact:
Gail Gallaher at 541-292-8775.

CENTRAL OREGON REGION
Second Wednesday of every month
11:30am - 12:30pm
St. Charles Medical Center
2500 NE Neff Road
Bend, Oregon

For more information and directions contact:
Betsy Paige, LMSW, at 541-977-7502.

Want to request a topic for discussion or presentation?
Get in touch with your local regional services coordinator
or contact Karen Galloway, Care Services Director, at
503-238-5559 ext 100.

Do you receive two or more copies of this Newsletter?
If so, please let us know. Help us save valuable resources in both printing and postage costs.
Contact Maggie at 800.681.9851 ext 103 or info@alsa-or.org.
Thank you for helping us update our databases.

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