Chapter Honors Kim Goslin with $150,000 Research Gift in her Name

On Saturday March 8th, 2014 over 650 people gathered for our annual Dinner and Auction Gala. One of the highlights of the evening was awarding the ALS Hope Award to Dr. Kimberly Goslin, Medical Director of the Providence ALS Center. Her dedication, hard work and spirit of hope has reshaped the landscape of ALS care in the Pacific Northwest over the last decade.

In recognition of Dr. Goslin’s dedication to treating people with ALS and to finding a treatment for the disease, the Board of Directors of The ALS Association Oregon and SW Washington Chapter honored her, by contributing $150,000 to the national ALS Association, TREAT ALS™ Research Program in her name. This contribution is a gift in addition to the chapter’s regular contributions to ALS Research.

“We are thrilled to be able to honor Kim Goslin’s passion for helping people with ALS,” says Dr. Lou Libby, ALS Association board member. “More than any clinician I know she exemplifies the spirit that we can always do more for our patients. Being able to honor her with a research gift is thrilling to us as a board, as we share the hope with Dr. Goslin that there will be a treatment for ALS soon.”

The funds donated to The ALS Association’s TREAT ALS™ Research Program will go towards basic science to understand the mechanisms involved in ALS and translational research that take ideas from the lab bench to the clinic.

To view a tribute video in Dr. Goslin’s honor that was debuted that night, visit the chapter’s YouTube page at www.youtube.com/user/ALSAOregon.
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:

- Jim Baber
- Harper Bates
- Robert Beat
- Patricia Belcher
- Marion Berg
- Robert Bohnen
- Karen Brusse
- William Byers
- Sabine Clark
- Betty Cook
- Earl Cox
- Cathy Curths
- Joseph Denman
- Kim Elliott
- Bill Gabel
- Robert Hawkins
- Pauline Heckman
- Ralph Heckman
- Thomas Hendrick
- Kathryn Hillesland
- Charles Hopkins
- Edwin Horn
- Randy Kyte
- Gordon Malcom
- Robert Menzel
- Marilyn Palmer
- Edna Stanley
- Patricia Strunk
- Kay Thompson
- George Thurman
- Linda Wind

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 541-987-103 ext 103 with corrections so our records can be changed and updated.

Change in Leadership

Congratulations to Joe Gross with JGP Wealth Management Group of Wells Fargo Advisors and Matthew Bassist with Langley Investment Properties, as they assume the leadership of our Board of Directors. Joe (pictured left) is our new President and Matt (pictured right) is our new Vice-President.

Many thanks to our immediate past board President, Dr. Lou Libby.

Thank you all for your dedication to creating a world without ALS.

In Memory of Our PALS October 1, 2013 – January 31, 2014

| Patricia Belcher | Emily Bradbury |
| Sabine Clark | Betty Cook |
| Cathy Curths | Joseph Denman |
| Susan Drew | Janice Elser |
| Mary Francisco | Bill Gabel |
| Leah Hammer | Mildred Hatfield |
| Robert Hawkins | |

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

HOW TO REACH US | phone: 503-236-5559 or 1-800-681-9851 | fax: 503-296-5590 | email: info@alsa-or.org | website: www.alsa-or.org
Portland / NW Oregon / SW Washington

In the Portland Metro area, care services staff Lance Christian, Sarah Grist and Rachelle Preston continued to serve individuals living with ALS and their families through home visits, support groups, and multidisciplinary clinic representation. Lance Christian, Rachelle Preston continued to serve individuals living with ALS and their families through home visits, support groups, and multidisciplinary clinic representation. Lance Christian, Rachelle Preston continued to serve individuals living with ALS and their families through home visits, support groups, and multidisciplinary clinic representation. Lance Christian, Rachelle Preston continued to serve individuals living with ALS and their families through home visits, support groups, and multidisciplinary clinic representation.

Since our last newsletter we have offered some unique opportunities for members of our ALS community to engage in some educational and meaning making programs. Specifically, during National Caregivers Awareness Month in November, 10 caregivers of loved ones completed a 6 week session of Powerful Tools for Caregivers. Powerful Tools is a program offered by a local organization which teaches caregivers the ABCs of self-care and the role of a caregiver. If you or your loved one would benefit from extra support in the role of caregiver, please contact a member of the care services team to let us know you are interested in attending the next session of Powerful Tools which will be held at the Beaverton Library. This group meets the 3rd Wednesday of each month from 3:00-4:30. Please contact Lance Christian at ext. 110 with questions. All are welcome!

Additionally, the five participants of the early winter session of the Writing Life Stories class, facilitated by Judith Pulman, Literacy Arts Coordinator at the Multnomah Arts Center, not only worked hard to create powerful pieces of writing but also came together on December 11th in front of dozens of friends and family to read what they had written. It was an inspirational evening, with not a dry eye in the house. If you or your loved one is interested in participating in the next session of Writing Life Stories, starting the 2nd week of April, please let us know! It meets for 6 consecutive Friday afternoons from 130-300 in the Multnomah Arts Center. Novice and experienced writers all encouraged to attend.

In February, the Capitol and Willamette Valley Support Groups presented an educational program for respiratory therapists of the Willamette Valley. This program was attended by the Respiratory Care specialists who serve PALS all across our chapter by working at the local hospitals and medical community and raise their awareness around the care services team to let us know you are interested in attending the next session of Powerful Tools which will be held at the Beaverton Library. This group meets the 3rd Wednesday of each month from 3:00-4:30. Please contact Lance Christian at ext. 110 with questions. All are welcome!

Willamette Valley

Education was the focus for the past months in the Willamette Valley region. Mary Rebar, Regional Services Coordinator, presented an educational training for rehabilitation therapist at Providence Benedictine Home Health Services of Salem and Mt Angel. In February, Mary partnered with NW Medical, and a local PALS for an educational presentation at the Mohawk Valley Fire Department in Marcola.

Three young men at Blanchet Catholic High School, in Salem, chose to learn about ALS for their Senior Project by attending the Capitol support group, volunteering at the Ski to Defeat Valley Fire Department in Marcola.

Our ALS Loan Closet continues to be a very important asset in Central Oregon. Norco’s David Hamilton and his crew do a very good job of assisting in the delivery and maintenance of the durable medical equipment that has been donated for use by our PALS. This is a big job and very appreciated!

Betsy Paige, LMSW, Regional Services Coordinator facilitates the monthly support group, offers home visits, manages the ALS Loan Closet and is involved in the ALS Clinic. Please feel free to contact her for more information on the local services provided by the ALS Association in the Central Oregon area.

Southern Oregon

Regional Services Coordinator Gail Gallaher continues to serve people living with ALS in Southern Oregon through home visits, support groups and medical equipment loans. Recent support group speakers included Ellen Downes, OT on adaptive clothing and home devices; Kristi Scott, RN on respiratory care; Kevin Rowland of RJ Mobility on accessible vehicles; and Shana Tognazzini, SLP on alternative communication solutions. Support groups offer information and social support as members exchange experiences and ideas about living well with ALS.

In March, Providence Medford invited Shana and Gail to meet with a New England based organization who provided software on current speech generating technologies and to review our free services to PALS. Special thanks to Julie Mondz-Kleemann, MS, CCC-SLP for hosting the meeting and providing demonstrations. Gail and Shana also made several home visits to PALS with speech/swallow issues. We are grateful to Shana for sharing her expertise with local therapists and PALS.

Gail continues outreach to the medical community with a focus on neurology practices, and home health and hospice agencies. In January Gal was asked to return to the Oregon Health Sciences University nursing program at Southern Oregon University for a presentation on chronic illness and the family caregiver. Thanks, again, to Tiffany Allen and Dr. Glenise McKenzie for the invitation to engage with nursing students.

Community Partners make special things happen in every region, and we are fortunate to receive on-going support from Betty Johnson and Rae Eatherton. Each month they host a luncheon for PALS and their friends at the Medford Eagles Lodge. And this past January, they hosted their 2nd annual series of fund raising events at the lodge which generated over $5000. This fund is tapped throughout the year to help PALS with out-of-pocket expenses such as car and appliance repairs, help with utility bills, travel expenses, and ramp or wheelchair repairs. Thanks, Betty and Rae for your hard work and generous support!

Our additional thanks goes out to Laurie Sanderson of NuMotion who coordinates the movement of medical equipment from our loan closet in Medford. We’re grateful for volunteer and in-kind support from Delta Foods, Bobs Discount Foods, and the Medford Eagles Lodge. And finally, thanks to Right at Home Care Services for providing excellent care through our In Home Care Program.

As always, keep in mind our services are available to all individuals living with ALS and their families. If you would like to speak with a member of our care services team, please call us at 1-800-253-1234.

(continued on next page)
REGIONWIDE CARE SERVICES

Implementing Our Mission: 2013 By The Numbers

- Supported 427 families living with ALS across Oregon from Longview to Burns, from Brookings to Ontario. (and a few people in CA, Idaho, MT and others).
- Offered Medical Equipment loan program in Portland, Grants Pass, the I-5 corridor and Bend.
- Supported over 150 families in being able to communicate via our dedicated AAC position.
- Supported families in accessing healthcare, services and resources they need to live with ALS by providing over 600 home visits from our Care Services Staff.
- Hired Mary Rebar to fill our Willamette Valley Care Services position. Hired Rachelle Preston to fill our Portland Care Services position.
- Supported families by offering TIZ support group meetings across the chapter.
- Continued partnerships with the Paralyzed Veterans of America.
- Added new Quality of life programming.
- Powerful tools for caregiving classes.
- Write your life story class.
- Offered Professional Education on ALS to Providence Clinicians, Hospice & Home Health Agencies, Caregiving agencies and more.

Caregiver Spotlight - The Amazing Nic!
Greetings, my name is Kurt Mohs; my wife Nikki was diagnosed with ALS in October of 2005. I think our story is probably typical among people who have experienced this awful disease. My story today is about a very special caregiver who has made an incredible impact on our lives. This person comes to our home every day before his daily commitments. He helps Nikki put on her socks and sweater, makes her coffee, prepares breakfast and does all the little things that need to be done to make it possible for Nikki to make it comfortably through the day until he returns in the afternoon.

To me, what is so special is that the commitment this young man leaves for every day after he helps Nikki is his attendance at elementary school. He is 8 years old and he has been helping his grandmother every weekday for about a year. I leave early for work, while Nikki is still asleep so having someone there when she wakes up is such a relief for me. I know she has everything she needs for the day because of his special caregiver.

After school Nic (named after his grandma Nikki) comes back to our house, he reads to Nikki and makes her a snack and on a few occasions has made her dinner. When Nic spends the night he helps his grandma into bed and makes sure she has everything she needs. He takes over many of the things that I would normally do, and he does them with joy. He is still a typical 8 year old, he likes to take joyrides in the power wheelchair while watching Sponge Bob and he complains about doing his homework, but when Gramma Nics says she needs something, there is no better caregiver than him.

Thanks Nic and thanks to his mom Erinka for allowing him to be such an important part of our lives. We are truly blessed.

The Mohs family lives with ALS in Salem, Oregon.

Top 10 ALS Bits & Pieces
Advice from Glenn Asbury, a man living with ALS in Central Oregon

1. Attitude PMA Positive Mental Attitude. Having positive outlook on things and visualizing the best outcome goes a long way. You are amazing. Brush up on your computer skills. Use all the devices to make life easier and more enjoyable.
2. Education. Learn as much as you can about how the disease goes so you can recognize things when the start to happen.
4. Shaving your hair. I did this in the shower, my wife was so happy.
5. Embrace technology. The things we have available today are amazing. Brush up on your computer skills. Use all the devices to make life easier and more enjoyable.
6. Do it your way. Be in charge of yourself. I have been fiercely independent as much as possible, and haven’t always done things the “right way”, and have no regrets about it.
7. Stay active. Go places, do things. Get out of the house! I can’t say how many times I have thought, “this is the last time I may be able to do this”.
8. Use the help. Friends, family, DHS, Medicaid, Medicaid, ALS association, MDA, many private organizations. You don’t have to reinvent the wheel.
9. Lungs. Work hard at maintaining their health. Breath stacking is important. Get a Bipap machine as soon as possible. Don’t waste time and money on sleep studies.
10. Have some heroes. I’ve watched those who have gone before me. What did they do? What was it like? How did it look? Some of my favorites… Google Ben Byer, filmmaker of “Indestructible”, an ALS film (Netflix, and free copy to PALs). The Heywood brothers, film writing and directing team. Patrick O’Brien, at patrickoebrienfoundation.org, has lots of good video. Randy Paush, cancer stricken college professor, author of the “Last Lecture”, has a great video about what’s really important in the end.

And as Elvis said, “Thank you, thank you very much!"

Need An Extra Hand? Check Out Our In-Home Care Program
We continue to serve a limited number of families statewide through our In-Home Care program. Through partnerships with local caregiving agencies, this program provides and financially covers up to six hours of caregiving per week.

What kind of tasks can a caregiver do?
- Shampoo your hair
- Assist with assistance to the toilet
- Administer a PEG tube feeding
- Assist with stretching
- Help with dressing, including those pesky buttons or compression stockings

What are some benefits of caregiving?
- Provides a break for your family or other primary caregivers. This can help with stress reduction and prevent caregiver burnout.
- By allowing a caregiver to help they provide energy conservation. This allows you to spend your time and energy on the important things you love to do!
- Caregivers can help establish a routine as they come on a set schedule that best meets your needs.
- They provide companionship and an opportunity to engage in the community without leaving home.

What do participants have to say about the program?
I wanted to thank you for providing me with a caregiver. It has taken some of the burden off of my family and me. My caregiver is bubbly, refreshingly kind and refreshing and enjoys helping me. I knew this would help my family but it surprised me by how it’s been a big help to me. Emotionally, I feel better. I hope the program is going well and I’m grateful for it. Thank you."

“The caregiver program you gave to us is a real help. It can’t take care of everything. But we use the caregiver to help me take a shower two times a week. These are the only showers I get, otherwise it is sponge baths. I feel so much better!”

We continue to accept applications for our waiting list.

If you are interested in applying or have questions please contact Regional Services Coordinator, Rachelle Preston or homecare@als-or.org.

A newsletter from The ALS Association Oregon and SW Washington Chapter
Thank you to our 2014 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, JGP Wealth Management, Wells Fargo and Numotion
Registration is now open for the 2014 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 7
NEW LOCATION! Bear Creek Park, Medford, Oregon
Contact Rebecca Pace for more information.

Southern Oregon Walk to Defeat ALS®
Sunday, September 8

State Capitol Walk to Defeat ALS®
Sunday, September 13

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

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

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

Your Walk Coordinators 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 x106 or RebeccaPace@alsa-or.org. Julia Mayfield can be reached at 800-681-9851 x107 or JuliaMayfield@alsa-or.org.

We’re The Coolest!
We are excited for another successful walk season and are THRILLED to be awarded “The Coolest Corporate Sponsorship” and “Most PALS Participants at a Walk” at our Portland Metro Walk this past February at the National Winter Walk Forum!

Marianne Sansour and her family hosted a benefit night at Burgerville in their hometown, The Dalles, Oregon.

David and Patti Cofer, who live in Junction City, secure the Olive Garden as sponsor for the Willamette Valley Walk.

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Events

Central Oregon Walk to Defeat ALS®
Saturday, September 7
Riverbend Park, Bend, Oregon
Contact Rebecca Pace for more information.

Southern Oregon Walk to Defeat ALS®
Sunday, September 8

State Capitol Walk to Defeat ALS®
Sunday, September 13
State Capitol Grounds, Salem, Oregon
Contact Julia Mayfield for more information.

Willamette Valley Walk to Defeat ALS®
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Event will be a Metric Century Challenge for those who know they can cruise past the 50 MILE CHALLENGE!

Here are the basics about the Ride to Defeat ALS:

- Family Fun Ride, 25 mile, 50 mile, Metric Century or Century Challenges
- $35 Registration Fee for Adults
- $25 Early Bird Registration before May 1st
- $15 Registration Fee for Children
- $10 Early Bird 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 2014 Ride to Defeat ALS VIP Jersey, or $1000 for them BOTH!

Matt Miller has participated in the Ride to Defeat ALS twice, riding the 50 Mile Challenge. He shares why he’ll be back in 2014. “The Ride to Defeat ALS is my favorite benefit ride ever. Besides it being for a worthy cause, the ride is one of the most scenic rides in the Willamette Valley. The ride is well supported and the food at the rest stops, and the meal at the finish line, have got to be the best of any of the benefit rides around.”

Contact Aubrey McCauley, Development Director, at 503.238.5559 ext 105 if your company would like to be added to this list.

Our 2014 Regional Walk Sponsors
Contact Aubrey McCauley, Development Director, at 503.238.5559 ext 105 if your company would like to be added to this list.

For more information, contact Aubrey McCauley at ride@alsa-or.org or 800-681-9851 x106.
Congratulations Lou!

The ALS Association Oregon and SW Washington Chapter is thrilled to share that our immediate past board president, Dr. Lou Libby, has officially been elected to serve on the National Board of Trustees for The ALS Association.

While continuing to serve on our local chapter board, he will also lend his professional and personal experience and our local voice to help guide our organization towards a treatment and a cure! Congrats, Lou!

GIVING

$$ Million Dollar Update

Because of your support and participation in our 2013 Ski to Defeat ALS, Ride to Defeat ALS and Walk to Defeat ALS® events, we hit a HUGE milestone! For the first time in our chapter’s history, these three events combined raised over $1,000,000! Yes, you read that right... over ONE MILLION DOLLARS! AMAZING! FANTASTIC! EPIC!

Trevor Leaman presented a check to our Development Staff for over $5,000 from his Winter Ale Fest, a community event in support of the Walk to Defeat ALS®. With support from Brittany Graham, Charanne Graham, Rhonda Cahill, Micah Hilario and many others, this awesome event was the final push to get us to the One Million Dollar mark.

Many special thanks to our supporter who offered the $25,000 matching challenge to encourage everyone to take the extra step to hit this goal!

What does One Million Dollars mean?

RESEARCH - funding critical trials to find a treatment NOW! Funding to understand the genetics and environmental factors that contribute to ALS, the building blocks to find a cure.

LOCAL CARE SERVICES - support groups, creative funding, assistive technology support and services, in-home care giving funding, ALS specialty care clinics, home visits with professional social workers, bereavement support, children support programs and so much more.

PUBLIC POLICY - advocacy in Washington DC and in our local state capitol for ALS research dollars, National ALS Registry funding, veterans services and more.

We so appreciate the generosity, passion and commitment from you and thousands of your fellow community members who joined you in this epic accomplishment! With everyone doing their part in this critical fight, we will create a world without ALS!

From the bottom of our hearts and in honor of everyone touched by ALS, THANK YOU!

Until there’s a cure, your Staff and Board of Directors The ALS Association Oregon and SW Washington Chapter

Circle of Hope

Below are individuals, corporations, and foundations that have joined you in dedicating yourselves to the fight against Lou Gehrig’s Disease. We would like to honor them by simply saying THANK YOU. All of them have demonstrated hope, strength, determination, and courage... and all are inspirations to each and every person in our community that is touched by ALS.

Our Heroes: $100,000 +

Mr. Jon Bucasa

Our Inspiration: $10,000 to $20,000

Alpenrose Dairy
The Kenneth and Jean S. Libby Foundation
Dr. Louise and Bernie Krummel and Jeff Bendanzo

Our Hope: $5,000 to $9,999

Trina and Brian Libby
Tina and Steve Sall
Wells Fargo Foundation
Wells Fargo
Fred Meyer Stores
OCF Joseph Weston Public Foundation
Debra and Randy Cadamuro
Sally and Jim McAtee
CARE Medical Equipment
Morgan Stanley
Portland General Electric
Terry and Jay Allison
Mr. Scott Funeral Home
Linda and Steven McGeeary
Rover Family Foundation
The Standard
Washington USA, LLC
Cheryl and Nick Ragonesi
Community Health Charities of Oregon
Kaye and John Condon
Stephanie and Robert Sall
Ms. Marcia Bagrell
Providence Health and Services

Our Courage: $15,000 to $24,999

Jeanne and Mac Butler
Mr. Joseph Speight
Judith and Paul Newman
Phyllis and Carl Cadamuro
Doug Greenberg
Traci Williams
Patty Overlund and Ian Deak Farms LLC
Debbie and Kenneth Willet
Getting Eden Development Co.
Yvonne and Terry McCoy
Vera and Earl Cherry
Ms. Chera-Lyn Roberts
Duma Camayo Allen Higgins & Tongue
Claudia and Doug McIner
Ann and Mark Eden
Mr. John Alexander
Ms. Patricia Bosse

Dana and Anita Cadamuro-Hussey
Ms. Mary Beth Baker
Mentor Graphics Foundation
Ms. Mary Feltz
Nustumon
Alyce and Tom Mercer
Terrapark Events, Inc.
Wells Fargo Community Development
Colliers International
Pacific Northwest Properties
Cynthia and David Greene
Barbara and James Lobbied
Pink Marton Inc.
Frank and Jane Grey
Stewart Sinclair & Grey, LLC
Alliance Healthcare Foundation
Ms. Elizabeth Berman
Marion and Cale Stand
Mr. John Ermeling
Jean and Tony Shields
Mr. Greg Ruch

Our Determination: $5,000 to $8,999

Korin and Steven Weeks
Jenice and Richard Romano
Catalyst Capital Management, LLC
Ms. Timothy Wallace
Dorson Ernst and Bob Booth
Betsy and Michael O’Gara
Suzanne and Andre Perras
Portland Monthly Magazine
Mr. Christopher Kigwin
Ms. Kelly Bresnau
Phifes Robotics Inc.
Mr. Tim Gerth
Leanne and Mark Raver
Carolyn and Earl Porco
Ms. Cathy Stouffer
Wall-Mart Foundation
Mr. Steven Halley
TIAK Architecture Inc.
RTS Associates
Mr. Chuck Kirkong
Northstar Chemical
The Costa & Donald Barker Foundation
Leather and John Foundation
Equity Group Foundation
Tektronix Inc.
Elizabeth and Michael Kiteimer
Jenice and Robert Hoveum
Kalen Mornack
Memorial Golf Tournament
The Peterson Family Golf Fund
Emry & Sons Construction Inc.
Ms. Elizabeth McCaffery
Maybelle Clark MacDonald Foundation
Wachovia Employee Benefits
Specit Development Inc.
Title Insurance Co.
Ms. Sally and Thomas Puye
Mr. Robert Hoffman

For the purposes of this listing, only total cumulative monetary donations have been listed as of December 31, 2013. Names of donors are listed in descending order of total cumulative monetary donations received. For those individuals, corporations and foundations who are no longer with us.

If your name has inadvertently omitted or listed inaccurately, please accept our sincerest apologies. If your name is not included on this list, please contact our office immediately at 800-155-9887 or 7 by email at Advancement@alsoregon.org

Thank you to our 2014 Year-Round Partners: Alpenrose Dairy, Fred Meyer, Northwest Medical, JGP Wealth Management, Wells Fargo and Nustumon
Meet the Carnahans!

Cindy and Mike Carnahan are the best kind of people we wish we didn’t have to know. Knowing many families dealing with ALS, we find ourselves using that phrase often. And what we mean by that is that we wish we could know them under better circumstances, not ALS circumstances. Mike Carnahan has ALS, but instead of letting that consume him, he and his wife chose to let it empower them to do something. And do something, they have. From the Ride to the Walk to Community Booths to Auction Procurement and so much more, the Carnahans have dedicated their time and talents to our cause. And that is why we highlight them in our Volunteer Spotlight this Spring.

“Mike and I have a long history of volunteerism. Throughout our lives we have been involved with many different groups serving our community.

In many instances the groups we helped relied solely on volunteers to get the work done. As an electrician with IBEW Local 48 Mike volunteered his time to the Vancouver Sausage Fest, the Grotto and his biggest and favorite project for several years, and the temporary power for the Fort Vancouver Annual Fourth of July festivities.

We surely never imagined Mike would be diagnosed with ALS, but in 2013 he was. While we don’t have a calendar of what the future holds for us, we have chosen to focus our volunteer efforts with the ALS Association. From the Ride to the Walk to helping with the Gala, it is important to us to step up to help as much as we can while we are able. We have reaped far more benefits than the hours we have put in this first year. Not only is it a wonderful way to meet fellow PALS, we have met so many wonderful folks that simply support the cause.

“It does matter!”

Cindy and Mike, the work you do certainly does matter. And while we wish the circumstances were different as we often do, we SO very happy to know you. You are helping to do something, they have. From the Ride to the Walks to helping with the Gala, it is important to us.

Cell-to-Cell Spread of Misfolded ALS Protein Seen in Cell Model

Washington, D.C. (February 25, 2014) — Scientists have demonstrated a potential new mechanism for the spread of ALS disease pathology in cell models, whose results may point to possible new therapeutic strategies. The study was published in the journal Proceedings of the American Academy of Sciences.

ALS (amyotrophic lateral sclerosis), often referred to as Lou Gehrig’s Disease, is a progressive neurodegenerative disease that affects neurons (nerve cells) in the brain and the spinal cord. Eventually, people with ALS lose the ability to initiate and control muscle movement, which often leads to total paralysis and death within two to five years of diagnosis. There is no cure and no life-prolonging treatments for the disease.

Mutations in the gene for superoxide dismutase 1 (SOD1) are a cause of about 20 percent of inherited ALS. Misfolded mutant SOD1 protein is believed to contribute to the disease process in those carrying the mutation, but the role of misfolded non-mutant protein in the disease is unclear. The researchers in this study, led by Neil Cashman, M.D., of the University of British Columbia, Vancouver, Canada, showed that both misfolded mutant protein and misfolded normal protein can be released by one cell and picked up by another cell. The uptake of misfolded protein can lead to misfolding of normal protein in the cell that takes it in, propagating the misfolding process from cell to cell. That cell-to-cell transmission could be reduced by antibodies against the SOD1 protein.

“These results are intriguing and potentially important in understanding the ALS disease process,” said Lucie Bruijn, Ph.D., MBA, Chief Scientist for The Association. “If the spread from cell to cell seen in this cell model also occurs in people with ALS, it could help explain the progression of the disease after it begins and point to blocking that spread as a new and important treatment strategy, including for individuals with non-SOD1-related ALS. However, more work will need to be done to determine whether misfolded SOD1 does in fact move from cell to cell in humans and whether this process contributes to the pattern of disease progression we see. Answering these important questions takes on new urgency with the publication of this study.”

Indeed, one approach to therapy would be to treat with antibodies against misfolded proteins. Several groups have shown that this strategy has benefit in the SOD1 mouse model of ALS, and investigators Janice Robertson, Ph.D., University of Toronto, Toronto, Canada and Joan Coates, University of Missouri, Mo., are testing this approach in a canine model of ALS in a study funded by The ALS Association.

Upcoming Volunteer Opportunities!

We have many exciting volunteer opportunities coming up in the next couple of months. Whether you’re a cyclist, love the Walk, or just want to represent our organization, we have a job for you! For more information contact Rebecca Pace, Development Manager, by phone at (503) 238-5559 x106 or by email at volunteer@alsa-or.org.

**Rad Run**
Saturday, May 17

**Pioneer Century Bike Ride**
Saturday, June 7, Canby, OR

**Gorge Ride**
Saturday, June 14, The Dalles, OR

**Ride to Defeat ALS**
Saturday, July 12
Mt. Angel Festhalle, Mt. Angel, OR
The year 2013 saw major developments in new therapy approaches for genetic forms of ALS, especially for the most common genetic cause of the disease, mutations in the C9ORF72 gene. Association-funded scientists made progress in understanding important elements of the disease’s pathogenesis, which will guide the search for new treatments. The Association also sponsored several meetings to advance both understanding of the disease and the more rapid development of clinical trials.

Improving Clinical Trials

The entire ALS community was disappointed in the negative results from the dexpramipexole trial. However, major lessons were learned in the design and execution of the trial, which will translate into improvements in similar trials in the future. Taking the lead in the effort to ensure trials are as rapid and efficient as possible, The Association co-sponsored a frank and probing roundtable discussion among experts on strategies to improve clinical trial design. Outcomes from this meeting will be used to improve future trials.

One key agreement among ALS clinical researchers and drug developers is the need for biomarkers to track disease progress and response to therapy. To further that effort, The Association awarded funds to several groups to develop clinically relevant biomarkers that can be used in future trials. In partnership with the American Academy of Neurology, it is providing support through the Richard Olney Clinician Scientist Development Award in ALS to a researcher to further develop immune-system biomarkers of disease progression. The Association also partnered with the Neuronal Clinical Research Institute (NCRI) of Massachusetts General Hospital to fund a clinical pilot study of an immune-modifying agent called tocilizumab, which will incorporate biomarker measurement. The Association is also funding a trial of the drug mexiletine, for treatment of muscle cramps, an important source of discomfort for people with ALS.

Progress on Understanding the C9ORF72 Disease Gene

Mutations in the C9ORF72 gene cause up to 40 percent of familial ALS and up to 6 percent of sporadic ALS. Thus, understanding how these mutations cause disease, and determining how to stop their effects, has the potential to improve the prospects for a large fraction of people with ALS. Association-funded scientists made major strides in both these goals this year, just two years after the discovery of the gene. Key findings announced this year included:

- Gene mutations form sticky aggregates of RNA, which bind other cell molecules. Loss of these molecules may be central to the effects of the mutation.
- The mutation leads to the production of unusual small proteins, called RAN products. The effect of these proteins is unknown and is an active area of research to determine if they contribute to disease.

- “Antisense” therapy against the mutation reduces the amount of aggregated RNA and may be therapeutic, according to experiments in cell culture. In mice, antisense against the mutant gene appears to be safe, setting the stage for development of clinical trials. Antisense against the SOD1 gene has been shown to be safe in people with ALS.

Understanding Disease Pathogenesis

“Pathogenesis” refers to the many steps that lead to disease. By understanding these steps, it is possible to design therapies to interrupt them or mitigate their effects. Key developments in understanding pathogenesis included:

- In work supported by The ALS Association, researchers identified a unique molecular “signature” for a type of immune cell in the brain and spinal cord believed to contribute to ALS.
- Association-funded researchers showed that an ALS-related protein is involved in clearing RNA-containing material that builds up in cells, including neurons. The finding suggests that loss of that clearance ability may contribute to the disease.
- Researchers supported by The Association demonstrated that cells that normally support neurons in the spinal cord instead worsen ALS in an animal model involving the disease. The Association also sponsored a major scientific meeting on how aspects of evolution and development affect the differential susceptibility of motor neurons. Understanding why some neurons are less vulnerable than others may lead to better strategies to protect neurons most susceptible to disease.

Major Funding Initiatives to Speed Therapy Development

The ALS Association awarded more than $5,800,000 dollars in new grants this year through its Translational Research Advocacy Funding Therapy for ALS program (TREAT ALS®). Awards were made through grants, drug discovery contracts and clinical research grants. TREAT ALS funds were also made available to fund a clinical pilot study of an immunomodifying agent called tocilizumab, which will incorporate biomarker measurement. The Association is also funding a trial of the drug mexiletine, for treatment of muscle cramps, an important source of discomfort for people with ALS. The Association currently supports a portfolio of over $20 million in research awards.

Educational Initiatives for the ALS Community

Again in 2013, The ALS Association sponsored monthly webinars featuring prominent ALS researchers. Each presenter provided a lay-level overview of their latest research, which spanned the field from new genetic discoveries to the search for biomarkers and development of experimental therapies. Through its partnership with the Northeast ALS Consortium (NEALS), The Association also continued sponsorship of The ALS Clinical Research Learning Institute (CRLS), an intensive program to improve understanding of clinical trials and to train people with ALS and their caregivers to become advocates for ALS research.
SOUTHWEST WASHINGTON REGION
Second Wednesday of every month
4:00pm - 5:30 pm
Southwest Washington Medical Center Memorial
Campus Fr/Willow Conference Room, Basement Level
(Enter building through Urgent Care entrance, Take elevator to Basement, Conference room is to the left.)
100 E. 33rd St. (Just off Main St.)
Vancouver, Washington
For more information and directions contact:
Sarah Greenstein, MSW 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
4:00pm - 5:30pm
Legacy Meridian Park Hospital
Health Education Center Room 106
19300 SW 65th Ave.
Tualatin, Oregon 97062
For more information and directions contact:
Gail Gallager at 541-292-8775.

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
2880 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 Gallager at 541-292-8775.