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. As Brenda and Bub Wright of Burns, Oregon have learned, the whole family has ALS, not just one person. The Wrights were living a storybook life in rural Oregon until a few years ago. With kids away at college, they were getting set to enjoy all the fruits of an empty nest. Bub was then diagnosed with ALS and the plan for life changed. Because of progressive weakness, Bub could no longer work at his job with Malheur County, and he had to give up his pilot’s license and sell his beloved small plane.

Accessing quality healthcare at the Providence ALS Center and with local healthcare professionals in Bend, Bub learned to live with the disease, but it continued to progress. Today, Bub can no longer stand and now uses a power wheelchair 100% of the time. He has also lost his ability to speak and is now an expert user of his speech generating device so that he can communicate with his family and direct his care.

With all these changes, Brenda has had to shift gears quickly from wife and mother, to caregiver. With the support of a flexible employer, Brenda is now working just a few days a week, so that she can be home with Bub. Caring for someone with ALS is hard and rewarding work. As Brenda said, “We work hard to get through each day and we are still trying to make each day special.” Special days like the date this last January when they celebrated their 25th wedding anniversary.

But even with the satisfaction of caring for the person they love, at times family caregivers like Brenda 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, burnout and to recharge their batteries caregivers need a break now and again.

Brenda and Bub are one of the many families who have used the The ALS Association Respite Care Grant Program from the Oregon and SW Washington Chapter. They utilized this program to hire extra help to care for Bub. In Brenda’s words “Respite care is great…Everyone is always asking what they can do, many want to come and sit with him. But since Bub now requires such specialized care not just anyone can take care of him. Having extra funds to hire the right personnel, allows the rest of the family to have a break. This is a wonderful feeling to have this offered from the chapter who knows how much it is needed. Once again, thank you so very much for this assistance. It is such a help!!”

This program is available for the use of people with ALS and their families residing in Oregon and SW Washington. Due to the great support the chapter received in the 2010 Walk to Defeat ALS®, we have been able to increase our respite care grants by 50%.

For 2011, up to $750 is available per family to hire non-family caregivers to give the primary family caregivers a break to rest, enjoy a favorite activity, take a vacation, and recharge their batteries. For information about The ALS Association Respite Care Program, please contact chapter headquarters at 800-681-9851 or talk with your regional services coordinator.
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.

October 8, 2010 – February 16, 2011

Romuald Bailey, Jean Marie Barnwell, Eugene Barrett, Patricia Boughton, James Bradfield, Charleen Braunbeck, Clyde Brown, Francis Chun, Julene Clark, Chris Cole, Lynn Cranell, Robert Dennison, Clair Drake, James Goodwin, Edward Green, Johnny Harris, Thomas Horn, Kathy Hrabik, Brad Johnson, Kathleen Kaczke, Mary Meikle, Rawlie Oldham, Mary Oliver, Gary Robb, John Robustelli, Larry Seals, Cecelia Stampley, Jim Steger, Myra Stewart, Merlie Thompson, Dorothy Uehlinger, Larry Ward, Eric Werts and Susan Wise.

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

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

WIN A FANTASTIC GETAWAY!

Your support will help bring FREE services to local families affected by Lou Gehrig's Disease. Enter to win your choice of 1 of the 2 INCREDIBLE vacation packages below:

Contact our chapter at info@alsa-or.org or 800-681-9851 to learn more about this AWESOME opportunity!

Drawing will be held on Sunday, June 19 2011 in honor of Lou Gehrig's Birthday. NEED NOT BE PRESENT TO WIN!

All Prize Packages are valid for travel through July 2011. Travel dates subject to availability and airline schedules. Blackout dates and other restrictions may apply. You must be 18 years old or older to purchase a raffle ticket.

COSTA RICA for TWO

Round-trip airfare on American Airlines for 2 plus enjoy 5 nights including breakfast for 2 at Marriott® in Tamarindo and/or Playa Herradura.

Suggested Retail Value: $6,490

SAN DIEGO for FOUR

Round-trip airfare for 4 and 4 nights (one room) at the Hyatt Regency Mission Bay Spa and Marina with admission to 2 of the following 3 San Diego theme parks: SeaWorld, San Diego Zoo and LEGOLAND California.

Suggested Retail Value: $5,928

TICKETS
$25 EACH
ONLY 2,000 AVAILABLE!

Buy a raffle ticket today!
May is ALS Awareness Month!

We are thrilled to announce partnership with the following local businesses in celebration of our efforts.

Crosley Lanes - Vancouver, Washington
– Inaugural Bowl-a-thon on May 1, 2011

Chevy’s Restaurant - Lake Oswego & Clackamas
– Benefit Night on May 2, 2011

Pastini at the Old Mill - Bend, Oregon
– Benefit Nights May 2-5, 2011

Pappy’s Pizzeria - Bend + Redmond
- Benefit Night on May 25, 2011

Please visit www.alsa-or.org for information or call 800-681-9851.

Join in our efforts or share with us an idea to partner with other local businesses.

National ALS Registry Enrollment Underway!

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

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

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

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

Please visit http://www.alsa.org/policy/registry.cfm today to learn more.

Our chapter goal for 2011 is to get 500 new advocates signed up to help with efforts such as these.

Visit http://capwiz.com/alsa/mlm/signup/ to sign up as a local advocate – our National Advocacy Office as well as our local advocacy efforts will keep you up to date on important issues and pressing requests for you to reach out to your local representatives.

Together, we can make a difference!

Central Oregon
Regional Services Coordinator
Kathleen Ronning
ph: 541-977-7502
e-mail: KathleenRonning@alsa-or.org

The ALS Association
P.O. Box 1855
Bend, Oregon 97709-9998

Southern Oregon
Regional Services Coordinator
Gail Gallaher, M.Ed.
ph: 541-292-8775
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The ALS Association
2305 Ashland Street, Ste C, Box 458
Ashland, OR 97520

THANK YOU TO OUR 2011 YEAR-ROUND PARTNERS

CARE
Medical & Rehabilitation Equipment

NW MEDICAL
Regenerative & Homecare Specialists
NW Oregon & SW Washington

Lance Christian, MSW and Betts Peters, MS CCC-SLP, continue to see people with ALS across the region. Lance has met with 24 families newly diagnosed with ALS in November, December, and January. In the last 3 months, we have led 12 ALS support groups from Salem to Vancouver. Around 140 people have attended. Lance has been busy supporting multiple families in creating “Share the Care” groups. This is a great model that helps families take all those people who say, “what can I do to help?” and organizes them into a support network.

Because there is such a demand for services in this region, we are recruiting a half-time social worker to join our professional staff in the Portland office. This new position will support families living with ALS and will participate as a chapter representative at the Providence ALS Center. For a complete job description, see the posting on our website: www.alsa-or.org.

Our ALS Association Certified Center of Excellence at Providence Portland Medical Center continues to be the gold standard for care of people with ALS in the region. At each clinic, a family with ALS is seen by a multi-disciplinary team of healthcare professionals. The ALS clinic occurs weekly with six patients attending each time. At this time, the clinic is booked all the way until June and we are looking to add extra clinics to accommodate the ever-growing need. The ALS Association Oregon and SW Washington Chapter supports this center with staffing for each clinic and financial support. We are always grateful to Clare Cross RN, and Nancy Hoke, RN, our clinic nurse coordinators, who do a great job organizing all the details.

Our Assistive Technology Services Coordinator, Betts Peters, continues to work with PALS and their families on options for communication and computer access. In December, she attended the International Symposium on ALS, which was held in Orlando, FL. This four-day conference brought together hundreds of doctors, nurses, and other health professionals from around the world, to share ideas and research on ALS, its causes, treatments, and hopes for a cure. Betts attended presentations, poster sessions, and meetings with other speech-language pathologists and assistive technology specialists about communication devices and strategies, cognitive changes in ALS, and clinic practices, among other topics. Dr. Goslin from the Providence ALS Center and Gwen Jones and JoAnne Bernt from St. Charles Medical Center also attended the symposium. This event was a wonderful opportunity to meet ALS specialists from all over the world and gather ideas for improving the services we offer here in Oregon and SW Washington.

Southern Oregon/Eugene Update

Regional Services Coordinator Gail Gallaher continues support and outreach to PALS and their families while consulting with medical providers. Support groups in Medford and Eugene share information and resources about the challenges of living with ALS. Recent speakers include occupational therapist Ellen Downes and physical therapist Bill Pearce. Also, Joe Mitchell of the Financial Aid Center for Long Term Care discussed the process for qualifying for Medicaid without the need to “go broke” or spend down all savings; it is possible for a healthy spouse to minimize or eliminate the loss of assets.

Community partners at the Medford Eagles Lodge held their annual fund raiser, successfully ensuring another year of eased financial burdens. They have recently helped PALS with computer repairs, lodging for family during hospital stays, car repairs, medical equipment, and ramp materials. We deeply appreciate the stewardship of Betty Johnson and Rae Eatherton over many years of support.

In honor of National ALS Awareness Month, Gail will host a Celebration of Life gathering on May 14th from 2:00 to 3:00 PM at the Medford Library. Music will be provided by harpist Bonnie Walker. All are invited to bring photos and flowers for the memory table, and to share stories about their journeys living with ALS. This annual gathering continues to be an uplifting event with more laughter and gratitude than tears, where the spirit of community is richly felt and celebrated.

Central Oregon Regional Update

Kathleen Ronning, our Central Oregon Services Coordinator, continues to be active helping families with ALS and in raising public awareness of ALS.

On December 3rd of 2010, another Central Oregon ALS clinic was held at The Center. Also in December JoAnne Bernt, PT and Gwen Jones, OT both with St. Charles Medical Center attended the 21st Annual ALS/MND Symposium which was hosted in Orlando, Florida by the ALS Association. The meeting is one of the largest meetings in the world devoted to ALS research and treatment. The meeting had a dual focus: research into the causes of ALS and development of the best treatments and clinical care for patients. We are looking forward to their report to our support group in February at our monthly meeting.

We had great attendance at the National Caregivers month luncheon in November which was hosted by our chapter. In February, we will have the first of our quarterly no-host Caregiver Lunch Meetings on...
Relationship Management and ALS

By Barbara Bronson Gray, RN, MN

The stresses and strains of ALS can have a big impact on relationships. The problems and challenges people with ALS face day after day can put enormous strain on a wide range of relationships, including those with people at work, siblings, parents, children, and of course, spouses and partners. Some people say there are now three of you in any relationship: you, the other person, and ALS. But experts say there are a few things you can do to help ensure that your relationships will be as healthy and positive as possible:

Communicate, communicate, communicate. Don't assume the other person understands what you are thinking, what you need, or what you're going through. To the extent you are comfortable, share your thoughts and concerns. Let people know what you need and what you don’t need and encourage them to communicate back with you, too.

Listen, listen, listen. Your friends and family still need to be heard. Even as you deal with the challenges of ALS, be sure you listen to the everyday issues in the lives of the people you care about. Hear what is going on with them and help and encourage them as much as you can.

Acknowledge your losses. You shouldn’t try to pretend that the lifestyle or abilities you have lost or may lose aren’t significant. It's healthy to talk about what you miss and what you grieve. As you do, experts suggest you then move on to focus on what you can do now.

Care for your caregivers. The people you love are at risk for burnout, illness, fatigue and a loss of interest in activities they once enjoyed. Do what you can to help ensure their health and happiness. Find ways to encourage them to continue to pursue what they enjoy.

Strengthen your social connections. It’s important to continue to reach out to your friends and family, to stay connected, to get regular updates on their lives and to enjoy time together. You may be tempted to avoid social occasions because of your physical limitations, but push yourself to stay in the mix and see the people you enjoy. If you find yourself depressed or down, the presence of people you care about can be a big boost.

Be kind. No matter what one’s circumstance, kindness is essential to relationship management.

Statewide Services

continued from page 4

February 14th. Caregivers always find these meetings to be a fun way to connect, share and validate care giving experiences. Past care givers for people with ALS are always welcome and encouraged to join us. Please let Kathleen know if you are not getting these notices by emailing her at KathleenRonning@alsa-or.org.

We are looking forward to 2011 as another year of essential collaboration with our community partners especially the ALS clinic staff from St. Charles and NORCO staff who provide such a solid and reliable base of service to people with ALS in Central Oregon. We hope that those of you who have not yet attended our monthly support group meetings will join us this year and lend your energy, expertise and valuable experience to our group.

Ensuring Your Future . . . . And Theirs

Charitable Gift Annuities provide dependable income for you or for loved ones while helping in the fight against ALS. You make a gift to The ALS Association (our minimum is $10,000) and we agree to make payments to you for life—at attractive payment rates. You also receive a tax deduction for your gift. To receive a free personal illustration showing your payments and tax savings based on your exact age and gift amount, contact our Chapter.

What the Experts Say:

“A charitable gift annuity gives you income plus a tax deduction—and lets you help a worthy cause.”

—CNN Money

The ALS Association
Oregon and SW Washington Chapter
Lance Christian, Executive Director
info@alsa-or.org  800.681.9851
The ALS Association Oregon and SW Washington Chapter’s Annual Dinner and Auction Gala has become quite an event – often attracting an average of 450 guests into the room to help support those affected by Lou Gehrig’s Disease right here in our local community. This upcoming year’s event will be no different.

DATE: Saturday April 9, 2011  
Expected Attendance: 500 people
LOCATION: Grand Ballrooms at the Hilton Portland & Executive Tower  
Auctioneer: Graham Crow  
Master of Ceremonies: Margie Boulé, Writer & Performer

Over the last 10 years, this event has raised over a million dollars to help local families put up a strong fight against Lou Gehrig’s Disease. In 2011, our goal is to raise $250,000+ and with your help, we will. Our guests spend an average of $500+ per person, showing a real value in reaching this captive audience! The community’s involvement and financial support gives local families living with ALS access to the tools, equipment and resources they need to take control of their lives.

Evening’s opportunities include: Golden Ticket Raffle, Wine Grab Bags, Silent Auction of 100+ packages, Live Auction, Paddle Raise, Signature Cocktails, Restaurant and Dessert Frenzies, and much, much more!

Contact gala@alsa-or.org or 800-681-9851 if you would like more information.

Please consider attending, contributing an in-kind donation, or sponsoring this FABULOUS event! Your support is appreciated!
PLEASE JOIN US FOR

The ALS Association’s
NATIONAL ALS ADVOCACY DAY
AND PUBLIC POLICY CONFERENCE

Sunday, May 8 - Tuesday, May 10

JW Marriot Hotel
1331 Pennsylvania Avenue, N.W.
Washington, DC 20004

For additional information please call The ALS Association
toll-free at 1-877-444-ALSA, or visit our website at www.alsa.org/policy

Statewide Advocacy
Save the Date!

Monday, May 16th, 2011

May is ALS Awareness month. Join us in Salem at the State Capitol to raise awareness and to advocate for services and resources important to people living with Lou Gehrig’s Disease.

• Meet with your State Representatives and State Senators.
• Share your families’ story about living with ALS.
• Influence policy on healthcare and social services.

Look for more information to come via the chapter website and through email communications. Contact Lance Christian at LanceChristian@alsa-or.org or 800-681-9851 with interest, questions, and/or ideas.
It’s time to mark your calendar!

We hold six Walks throughout our region – we hope to see you at one or more of them! If you need assistance registering or would like more information, please call 800.681.9851 or email walk@alsa-or.org.

**Bend**  
Saturday, September 10th  
Riverbend Park

**Medford**  
Sunday, September 11th  
Bear Creek Park

**Salem**  
Saturday, September 17th  
Riverfront Park

**Eugene**  
Sunday, September 18th  
Alton Baker Park

**Vancouver**  
Saturday, September 24th  
Esther Short Park

**Portland**  
Sunday, September 25th  
World Trade Center

The Portland Walk to Defeat ALS® Kickoff will be held on Sunday, July 17th at Alpenrose Dairy!

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**Walk to Defeat ALS®**  
because you can

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**Working toward a world without ALS.**

The Walk to Defeat ALS® is heading for another record-breaking year, and we need your help to make it happen. This year, we are working to raise more than $520,000 for our local chapter’s patient services, advocacy efforts and research initiatives. These dollars really do make a difference and your involvement in this effort really does help.

This year we will be growing each of our six Walks throughout Oregon and Southwest Washington. We will be increasing corporate sponsorships and growing our nationally-recognized Corporate Effort (an initiative that brought in more than $60,000 in 2010 from local businesses and businesspeople). We will be working hand-in-hand with local Walk teams and throwing exciting kickoff celebrations across our region. It’s going to be exciting and we want you to be part of it.

You can register today by calling 800.681.9851 or by visiting www.WalktoDefeatALS.org. The website is new and improved, but remember that we’re here to help. Everyone who registers will automatically receive an online fundraising page that can be customized with photos, videos, and more. If you need help with building your team or fundraising, there are prewritten email messages that you can customize and send to friends and family. It sounds unbelievable, but walk participants who use these online tools can raise 10 times more than those who don’t.

Give us a call if you would like more information on this empowering event. The walk is a powerful tool when it comes to raising both funds and awareness about Lou Gehrig’s Disease. It really is that ONE event that anyone can be a part of and anyone can make a significant difference.
Wow. What an amazing year. Never before in our chapter’s history has the Walk to Defeat ALS® met the half-a-million dollar mark. Nearly 5,000 walkers showed up on Walk Day. As fundraisers and team members, you helped us surpass that milestone by a long shot. We know that asking for dollars isn’t always easy. We also know that through online fundraising, social media, wrap-around events, letter-writing campaigns, and plain-old person-to-person asking, YOU DID IT. **With an original goal of $430,000, the 2010 Walk to Defeat ALS® brought in $548,134!**

These dollars help our local chapter ensure that your local services are here to stay. We thank you for your ongoing support, passion and joined hope to defeat ALS.

### Bend, Oregon
**Total:** $54,344  
**Top Five Teams**  
The Spectators: $7,513  
The G Team: $5,790  
Team Greg Kemp: $4,620  
The Bob Squad: $4,510  
Team Glenn: $4,180

### Medford, Oregon
**Total:** $15,178  
**Top Five Teams**  
Team Barbara Jean: $5,875  
Team Al: $1,020  
Darla J. Borns: $860  
Dave’s Dashers: $469  
Willies Wonders: $388

### Salem, Oregon
**Total:** $35,039  
**Top Five Teams**  
Laurie’s Lions: $10,000  
Rob’s Friends and Family: $4,907  
Chuckie’s Entourage: $2,705  
Brooklyn’s Squad: $2,162  
EZ Team: $2,110

### Eugene, Oregon
**Total:** $31,685  
**Top Five Teams**  
Walkers for Jim: $5,550  
Nana’s Crew: $3,615  
We’re Back! Walk and Roll for ALS: $2,290  
Team Tunno: $1,699  
Pam’s Pals: $1,365

### Vancouver, Washington
**Total:** $47,746  
**Top Five Teams**  
Find a Cure for Eric: $12,867  
Jerry’s Helmsmen: $6,455  
Candilorà Cadets: $3,458  
Roberts’ Rebels: $3,190  
Robin’s Rockin Family: $2,725

### Portland, Oregon
**Total:** $364,139  
**Top Five Teams**  
Steve’s Wobbly Knees: $43,371  
Ram’s Fans: $36,255  
Red Wigs: $16,012  
NW Medical: Walkin’ the Talk: $10,043  
Gang Greene: $10,005

I walk to raise awareness and money so that every person living with ALS can get the love, support and care that they need - like my dad did.

**Andrea White, “Denny’s Dominators”**

I personally LOVE the Portland walk. You couldn’t ask for a better place to walk in downtown Portland, river all the way! You guys always make walk day exceptional! All the volunteers are always so helpful and you guys just do a superb job with making it so fun and friendly, even for first time walk teams.

Dealing with such a horrific disease is hard enough and the smiling faces and positive attitude that you see all around during the walk makes it such a wonderful day.

**Chrystal Moore, “Pa’s Little Angels”**

My favorite thing about walk day is just getting together with so many others who know exactly how you feel. Everyone is there together for the same reason - to spread awareness of such a horrible disease. Just to be a part of something so... special. To talk with other families who have lost or losing a loved one to ALS. It is the special bond you feel with so many strangers.

It is the unsaid words that you can read in others eyes as you look around...
Register Today!

It’s officially time to dust off those walking shoes! We know it seems early, but trust us. We know that those walkers who register early for the Walk are sure to be part of the biggest teams and also the most successful when it comes to raising dollars to directly support our mission. Signing up now will give you plenty of time to recruit team members, plan fundraising events, craft your letters, and decide on a team theme. Plus, you will be right on track for the staff here at The ALS Association to help you plan a kick-off for your family or corporate team. Besides, the walk is so much fun – why would you want to wait to get started?

Visit www.WalktoDefeatALS.org to register today.

Remember – Sign in with your username and password if you’ve been a participant in the past. It will save you time and energy not only with registration but all of your contacts and information from last year will be there for you!

If you can’t remember your old login information, just give us a call or shoot us an email. We’re happy to help you out.

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

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

We are currently looking for people to become part of the Walk to Defeat ALS®- If you would like to be part of the planning process, let us know!

One thought: WHY WALK?

the crowd. It is just such a touching time to just gather around the starting line and share with others. My favorite part is just being there!

Jacque Saylor, “Papa’s Farmers”

I loved the upbeat feeling. It felt like love was everywhere. It was also awesome to cross the first bridge surrounded by so many supporters and see the masses of people heading back across the second bridge. On a practical note, it was great to know both my sister (who is living with ALS) and my dad (he’s 90) could make the full walk together on the scooters that were provided.

Hattie Larrouy, “Sweet On Sheila”

I walk to honor and remember all of those who have walked before me and no longer can. I also walk to remember the most precious woman who ever walked the earth, my mom.

Holly Ito, “Nana’s Crew”

My girls and I walk because we know firsthand all that the ALS Association does for the local families and we want to raise awareness so the association can continue their care for other families living with ALS.

April Candilora, “Candilora Cadets”
Hope. Love. Walk. That’s really what it’s all about and this year, you can wear those words on Walk Day. Walk participants who raise $25 or more will receive an official Walk to Defeat ALS® t-shirt. You can help us increase our fundraising dollars and make a real difference in your community. Did you know that in 2010, only 37 percent of walkers took part in fundraising? So, we challenge you to ask three friends for $10, and secure your Walk t-shirt today!

Thank you to Corepower Yoga! On Christmas Day in 2010, they hosted donation classes in our honor – and we received over $350 for their efforts. Every little bit counts and just think of the awareness it brought.

Visit our webpage at www.alsa-or.org to learn more about how to follow us online!
Is ALS One Disease, or Many?

By Richard Robinson

As new discoveries are made about the causes of ALS, an important question arises: is ALS one disease or many different ones with similar manifestations? The answer to the question is important, according to Nigel Leigh, M.D., Ph.D., because it may shed light on differences between patients in disease prognosis and response to therapy, and this may help shape the conduct of clinical trials.

Speaking at the final lecture of the International ALS/Motor Neuron Disease Symposium held in Orlando, Florida and hosted by The ALS Association, Dr. Leigh provided researchers and clinicians with much to think about as they wrapped up their discussions. Dr. Leigh is a Professor at Institute of Psychiatry at King’s College in London (UK) and has been a leader in both clinical and scientific research in ALS.

Clinicians have long recognized that people whose symptoms begin in the lower limbs tend to live longer than those with onset in the bulbar (swallowing) muscles; however, the reasons for this difference in prognosis are not clear. According to Dr. Leigh, the fundamental question we have to ask is, “What is the biological significance of these differences?”

As new genes have been discovered in recent years, the ALS picture has grown more complex suggesting that there may be multiple primary causes of the disease. And mutations in at least one gene, called TDP-43, can cause both ALS and another disease, called frontotemporal dementia. It may be that the two diseases are two ends of a spectrum, a concept discussed by Virginia Lee, Ph.D., earlier in the meeting.

Dr. Leigh believes there is much more to come as new genetic tools will allow the discovery of more genes that influence ALS disease risk. The recent discovery of the VCP gene is one example.

The ideal classification system would group cases either by the underlying disease mechanism or by similar prognosis. “Either of these properties would enable a classification to be truly useful in clinical trials,” Dr. Leigh said.

Currently, most trials accept ALS patients of all types, despite differences in prognosis. This means, however, that a positive effect of treatment on disease progression may be missed, either because it might not be big enough to stand out from the natural variability among all the patients or because the treatment is effective in some ALS subtypes but not others.

“The key question facing researchers is whether we should be ‘lumpers’ or ‘splitters’ in classifying ALS,” Dr. Leigh said. “This needs to be resolved to make further progress in genetics, biomarker and drug discovery. The persistence in lumping patients in the clinical design of drug trials may be one of the main reasons for the lack of success in finding disease modifying therapies.”

There are practical difficulties with splitting, however. A major challenge in conducting any clinical trial in ALS is enrolling enough patients to achieve “statistical power,” meaning the results, positive or negative, can be considered definitive. If enrollment is to be limited to only certain ALS subtypes, they may be even more difficult to conduct, at least without a large increase in the number of patients entering trials. This challenge is one the ALS clinical trial community is currently grappling with.

Dr. Leigh and colleagues have made a start at defining subtypes relevant for clinical trials by analyzing outcomes among a large group of patients and looking for factors that best predict prognosis. They found that two factors predicted most of the variability among groups: site of symptom onset (bulbar or limb) and delay from first symptom to diagnosis, with longer delay predicting longer survival.

“This is not the final word on the subject,” Dr. Leigh hastened to add, but it may provide a jumping-off point for further refinement, with the goal of defining natural divisions among cases of ALS that can speed clinical trials. New insights from genetics may be the most important source of ideas to better understand differences among patients.

“The value of this type of approach is that it may allow us to design clinical trials to give us faster and clearer answers,” according to ALS Association Chief Scientist Lucie Bruijn, Ph.D. “We will continue to search for the best ways to understand ALS in all its forms, and to design therapies to treat each of them. We will also be seeking ways to increase trial enrollment to make sure the results of every trial are definitive.”

A Simple Way to Make a BIG Difference

A legacy gift through your will or living trust to The ALS Association can make a big difference in the fight against ALS. 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.

The Legacy Society

The ALS Association
Oregon and SW Washington Chapter
Lance Christian, Executive Director
info@alsa-or.org    800.681.9851
New Genes, New Clues About ALS

New gene discoveries have quickened the pace of research on the causes of ALS. Those discoveries were the focus of several presentations and many conversations among scientists at the ALS/MND Symposium in Orlando, sponsored by the Motor Neurone Disease Association, and hosted by The ALS Association.

The discovery of VCP, the newest gene known to cause ALS, was announced just prior to the meeting.

Two other genes, TDP-43 and FUS, were discovered within the past two years and have become the subject of intense research. They join SOD1, the first gene discovered for ALS and still the most common genetic cause known.

Virginia Lee, Ph.D., of the University of Pennsylvania, was a co-discoverer of TDP-43. “This discovery has had an enormous impact” on the understanding of neurodegenerative diseases, for two reasons, she said. First, TDP-43 mutations can also cause another neurodegenerative disease, called frontotemporal dementia, suggesting the two diseases are two ends of a single spectrum. Second, the involvement of TDP-43 points to RNA processing as a potentially central mechanism in disease. Cells use RNA for a variety of processes, most importantly for relaying genetic messages from the nucleus, where they are stored, to the cytoplasm, where they can be used to create protein.

Both TDP-43 and FUS are RNA-binding proteins, meaning they interact with RNA to help it do its job. It is not yet clear how mutations in these two proteins cause disease, but researchers are looking closely at the protein-RNA interactions, to see whether the mutations that cause disease disrupt the normal activity of RNA as a result. “The more we understand these pathways, the better we can use information to identify new targets for treating ALS. This is a really exciting time for learning more about the causes of ALS, and trying to find disease-modifying therapies,” Dr. Lee said.

Tom Maniatis, Ph.D., of Harvard University, is examining the effect of TDP-43 and FUS mutations on gene expression in motor neurons. The goal is to find “the needle in the haystack,” the change in expression that leads to disease, rather than the many others that are a result of it. For reasons that are not yet clear, TDP-43 mutations appear to cause changes in expression that are opposite to those of FUS mutations, despite the fact that both cause ALS. Further research may uncover the link between the two that sheds light on a common pathway. Other researchers noted that the two proteins interact, and that interaction may increase when one or both are mutated.

The effects of mutations in these genes are being explored in a variety of models, each chosen to highlight one or more aspects of the disease process. The hope is that this multi-pronged approach has the best chance of revealing the true problem each mutation causes.

Another recently discovered gene, called optineurin, is only found in a handful of families, but researchers are hoping it may reveal disease mechanisms common to many forms of ALS. Mutations in optineurin are known to increase inflammation, a process that may damage motor neurons, through another molecule called TNF-alpha. “If this hypothesis is true,” said Ryuji Kaji, M.D., of Tokushima University in Japan, “inhibition of TNF-alpha may be a key to disease-modifying therapy.” He pointed out that there are many drugs already known to inhibit this molecule, suggesting it may be possible to quickly test this possibility.

“There are still more ALS genes to be discovered,” said ALS Association Chief Scientist Lucie Bruijn, Ph.D. She noted that the most recently discovered gene, VCP, which occurs on chromosome 9, is not the only ALS-causing gene there. Further work will be needed to discover this still-unknown gene and to identify others that cause the disease. “By finding these genes, and understanding the pathways each works in, we can piece together a picture of ALS that will lead us to new treatments. Each gene we discover brings us closer to that goal.”

Sign up for our monthly e-newsletter – its easy!

At the beginning of each month, our e-newsletter update can arrive in your inbox and provide you with current activities that are going on with our chapter.

If you do not receive this now and you want to in the future, please visit our website at www.alsa-or.org. Scroll down to the bottom right hand corner and find the box pictured to the right – all you have to do is enter in your first name and email address and then click Subscribe – it’s that easy!

If you have any questions, please email info@alsa-or.org or call Aubrey at 800-681-9851.

Thank you to our 2011 Year-Round Partners: CARE Medical & Northwest Medical
When Deb Vaughn and her husband Robert heard that the Portland Trail Blazers were partnering with The ALS Association for an awareness night, they got excited. Deb and Robert love sports and are always looking for a reason to get their friends together. Living in Salem, they then realized that they probably couldn’t rally all of their local friends to attend the game. And then, they got even more excited.

The idea came up to host a Trail Blazers Viewing Party. It would be the best of both worlds. Friends, a Mexican fiesta for dinner, an exciting basketball game…and they could turn it into a fundraiser for The ALS Association.

Instead of asking their friends to buy tickets to the game and travel to Portland, they asked their friends to attend their party, eat the delicious food, and make a contribution to their local chapter of The ALS Association.

And, it worked. They gathered to cheer on the Blazers with Deb and Robert on January 9th in Salem.

“We had an awesome time planning this potluck with our friends. The Wagner’s provided the cozy house, the Kosmala’s helped with the food, the Emery’s brought a delicious apple pie for dessert and we provided the ALS goodies and donation materials. And the best part is that we don’t have to wait for a special occasion to do it again!” says Deb.

Thanks to both Robert and Deb, and their supportive group of friends. If you would like to host an event in support of The ALS Association, we would be happy to help! Email us at info@alsa-or.org or call 800.681.9851.
Below are individuals, corporations, and foundations that have dedicated themselves to the fight against Lou Gehrig’s Disease.

We would like to honor all of them by simply saying **THANK YOU**.

**Our Heroes: $300,000 and Above**
- Debbie and Jon Buccola

**Our Inspiration: $100,000 - $299,000**
- The Kenneth and Jane S. Libby Foundation
- Louise and Barry Kremkau

**Our Hope: $25,000 - $99,999**
- Mr. Jerry Nudelman
- P.M.P, LLC and Mr. Peter Perrin
- Trina and Jeff Bandelow
- Kimberly Goslin and Thomas Gazzola
- Northwest Medical
- Jamie and Michael Anderson
- Jocelyn and Louis Libby
- Wells Fargo
- Mr. Joseph Gross and Ms. Shelley Noyes
- Mr. Scott Funeral Home
- Terri and Jay Allison

**Our Courage: $15,000 - $24,999**
- Linda and Steven McGeady
- Washman LLC
- Patty Overtund
- Sally and Jim McAfee
- Gerding Edlen Development Company
- Jeanie and Mac Butler
- CARE Medical, Inc.
- Ann and Mark Edlen
- Portland General Electric
- Ms. Milli Davis
- Western Communications: The Bulletin
- Ms. Chera-Lynn Roberts
- Mentor Graphics Foundation
- The Standard
- Ann and Tom Mercer
- Wells Fargo Community Development

**Our Strength: $10,000- $14,999**
- Colliers International
- Morgan Stanley
- Pacific Northwest Properties
- Pink Martini, Inc.
- Traci and Doug Greenberg
- DeeAnn and Randy Cadonau
- Mr. John Ermatinger
- Ms. Jessie Shields
- Vera and Earl Cherry
- Ms. Mary Beth Baker
- Providence Health and Services

**Our Determination: $5,000 - $9,999**
- Cheri and James Beatty
- Mr. Joseph Weston
- Paula and Mark Foat
- Terri and Steve Sall
- Portland Monthly Magazine
- Cheryl and Nick Ragnone
- Mr. Christopher Killgore
- Ashforth Pacific, Inc.
- Wells Fargo Foundation
- Yvonne and Tony McVay
- RE/MAX Equity Group Inc.
- Providence Brain Institute
- Krystin and Matthew Basset
- Melissa and Michael Haglund
- PacTrust: Pacific Realty Associates, LP
- Nancy and Michael Phillips
- Carla and Steve Forsyth
- Our Associates LLC
- Ms. Barbara Adler
- Barb and John Deeming
- Laurie Chadwick and Lee Mercer
- Oregon Lumber Company
- Ms. Elizabeth “Betsy” McCool
- Warrenton High School
- Ms. Marcia Bagnall
- Ms. Kayrin Perkins
- Anne and Scott Weaver
- Claudia and Doug McClure

If your name has been listed inaccurately, please accept our apologies and contact our office at 800-681-9851.

Please note: For the purposes of this listing, only cumulative monetary donations have been listed as of 12-15-10. Italics denote those who are no longer with us.

Many Thanks to the following Foundations who have committed support to our chapter in support of our Respite Care Program:

- **The Autzen Foundation**
- **The Equity Group Foundation**
- **Wal-Mart Foundation**

The ALS Association accepts donations of stock certificates, mutual fund shares, and other investment securities.

Please contact our chapter for more information.
## 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. Legend 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  
2651 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

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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 by calling us at 800-681-9851 or emailing info@alsa-or.org. This will help us save valuable resources in both printing and postage costs.

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*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