Dear Friends,

The Oregon and SW Washington Chapter is big and a place of grandeur, but ALS knows no barriers. In every community from the high desert of Eastern Oregon to the lush Willamette Valley, from our cities and suburbs to our beautiful coastal communities, ALS touches the lives of the people we love and steals them away before their time.

Our Chapter believes every person with ALS has the right to top notch clinical care and comprehensive care services that help families maintain their independence and live well with ALS regardless of geography. Through our chapter wide network of staff, programs and affiliated ALS clinics and centers support is available. Regardless of geography, we strive to make sure no person, no family, is alone on their journey with ALS.

While we do everything possible to help families living with ALS now, there is one driving vision for The ALS Association, Oregon and SW Washington Chapter – To create a world without ALS. For myself, our board, our staff and community the work to accomplish this vision begins and ends with people living with ALS.

2017 saw steps to success taken with many clinical trials offered in our community and the FDA approval of the first new ALS therapy in 22 years – Radicava. While not a cure, this new treatment has been shown to slow disease progression in ALS. I am optimistic that there are new trials and new therapies on the horizon that will build on this success.

The energy of our ALS community is stronger than ever. Our chapter receives no government or insurance funding. Your support fuels our mission. I am grateful for all we have accomplished together and look forward to the advances ahead.

Sincerely,

Lance Christian, LMSW
Executive Director

OUR 2017 YEAR ROUND PARTNERS
The ALS Association fights every day for people living with ALS, leading cutting edge research to discover treatments and a cure for ALS and serving, advocating for, and empowering people living with ALS to live their lives to the fullest.

**CARE SERVICES**

466 People Living with ALS Served  
180 female / 286 male / 78 veterans

Over 550 Caregiving Hours  
provided by our In-Home Caregiving Program.

152 Families  
Enrolled in the ALS Chapter Grant Program for the reimbursement of ALS-related expenses.

663 Medical Loan Closet Requests  
For equipment to aid in daily living activities.

**RESEARCH**

- Our chapter funded $150,000 towards ALS research.
- The Nuedextra trial showed significant palliative effects on speech, swallowing, and salvation.
- A novel C9orf72 biomarker was identified, paving the way toward the upcoming C9orf72 antisense clinical trial.

**ADVOCACY**

Successfully protected the ALS Research Program at the Department of Defense resulting in $10 million in appropriations and ensuring its place.
GIVING PEOPLE LIVING WITH ALS A VOICE:
A NEW PARTNERSHIP WITH UNIVERSITY OF OREGON

“At eighty years young, I received a Tobii device that sat in the box until the lovely young ladies from University of Oregon visited and explained how to work the machine with my eyes. Who would of thunk, I could do this!” - Don
As his ALS has progressed, Don has gradually lost his ability to speak. A veteran who was diagnosed in 2006 with familial ALS, Don lives in Eugene approximately 110 miles from the chapter’s Portland office. Although Don received a speech-generating device through his benefits, he did not know how to use the equipment and it remained in its box, gathering dust.

Don’s problem is unfortunately a common one. In many areas further removed from Portland, there are not enough speech-language pathologists (SLPs) trained in serving people with ALS or using communication devices. With a lack of well-informed SLPs, people living with ALS in Eugene or other more rural parts of Oregon fall through the cracks.

To combat this challenge, The ALS Association Oregon and SW Washington Chapter launched a regional partnership with the University of Oregon’s Communication Disorders and Sciences program. Through this contracted partnership, our chapter provides both educational resources to increase the knowledge of student SLPs surrounding ALS as well as increased access to equipment, resources, and well-informed SLPs for people living with ALS in rural areas.

After multiple home visits from student SLPs, Don received the training he needed to use his speech-generating device. Thanks to an innovative new partnership, Don and others living with ALS can keep communicating, even after they have lost their voices.

PARTNERSHIP HIGHLIGHTS

**An Innovative Collaboration** | The University of Oregon Partnership was piloted in 2016 to meet the unmet need of a lack of speech language pathologists (SLP) trained in ALS in rural areas of Oregon.

**Increasing Access** | Since 2016, the partnership has provided one-on-one speech therapy to 14 people living with ALS outside of the Portland metro area. Currently, the partnership is serving Lane, Linn, Benton, and Marion counties.

**Improving Education** | All SLP students at the University of Oregon receive two hours of education focused on communication devices and the needs of the ALS patient base. In addition, two SLP students per quarter provide home visits which have resulted in 42 home visits and other trainings provided to people living with ALS.
Ann Martin tries to make everyday a good day. Although confined to a wheelchair, Ann participates in chair yoga, is in a walking group, and goes on road trips with Cameron, her partner and love of her life.

The ALS Association Oregon and SW Washington Chapter has been on Ann’s side since she received her ALS diagnosis in October of 2017. The chapter has provided ongoing care services for Ann so that she can continue to lead an active life full of the activities that she loves.

“I decided I was going to be a good advocate for myself and for other people living with ALS.” - Ann

Although relying on others for daily activities has been difficult for Ann, the chapter has helped her regain some of her independence. Ann is looking forward to using her next chapter grant to fund transportation assistance so that she can more frequently attend support groups and other community events. In partnership with Norco Medical, Ann has also received wheelchair modifications and a ramp to allow her to more easily leave the home.

Ann is staying active and remains hopeful. But she knows she can’t do it alone. Her family and friends, healthcare professionals, and the chapter provide her with the support system that she needs.
AN INSPIRATIONAL WALK

Molly March would do anything for Lyndon and Carol Gabriel, who have been her second set of parents after she lost her own parents in her 20s. Lyndon was diagnosed with ALS in 2015 and Molly and her family have been a helping hand and strong advocates ever since.

One of the largest ways Molly gives back and provides support for Lyndon and Carol is by serving as Team Captain for Team Gabriel at the Vancouver Walk to Defeat ALS.

At the 2017 Vancouver walk, Molly helped Team Gabriel raise almost $10,000. For 2018, Molly has set her sights on raising another $10,000 and helping more families facing ALS.

While serving as a support system for her own loved ones, Molly also wants her fundraising to impact the lives of other families affected by this devastating disease. Her goal is to bring relief to all families living with ALS who face financial burdens.

As Molly prepares for this year’s walk, she is motivated by the little moments and memories from last year’s event: her daughter holding Lyndon’s hand while walking alongside his wheelchair and Lyndon and Carol cutting the opening ceremony ribbon.

“Walking last year was inspirational. Coming together as Team Gabriel and seeing all of the other families coming together in honor or memory of loved ones brought tears to my eyes,” said Molly.

The Walk to Defeat ALS could not be possible without our individual and team fundraisers and our local corporate partners. For the 2017 Walk to Defeat ALS, local business members collectively fundraised over $115,000. Each year, we celebrate those local business members who raise at least $2,500 in the Portland Business Journal – visit bit.ly/CorpEffort to see the ad and full list.
BOARD OF DIRECTORS

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These community volunteers generously donated their time, treasure, and talents to provide strategic direction and oversight to our chapter.

ADVISORY BOARD

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_Providence Health & Services_

Anne Weaver
_Elephants Delicatessen_

Kenneth Willett
_Consultant at Incendii Corporation_
Members of The Legacy Society have expressed their commitment to our chapter through a very special and important form of financial support. These donors have named The ALS Association as the ultimate beneficiary of a planned gift.

Such gifts might include a bequest and/or charitable income gifts such as gift annuities, remainder trusts, or gifts of life insurance.

If your estate plans include The ALS Association Oregon and SW Washington Chapter, please let us know by contacting Stephanie Rudeen, Director of Donor Engagement, at Stephanie.Rudeen@alsoregon.org or 800.681.9851 ext 116. We would like to thank you for your generosity by including you in The Legacy Society.

Ms. Angelene Adler
Jeff and Trina Bandelow
Don and Heida Bruce
Anita and Dana Cadonau-Huseby
Mr. Lance Christian
Mr. Leonard Davis *
Ms. Barbara C. Deeming
Kathleen "Kaye" Eberhard *
Ken and Tina Feldhaus
Dr. Kimberly Goslin
Ms. Cynthia A. Greene *
Mr. Joseph P. Gross

In loving memory of my mother, Helen Gross

Ms. Alexis Halmy
Matson Haug * and Julie Isaacson
Candace Kramer and Drew Prell

Randy *and Debi Kyte
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Ms. Corliss Sherry
Ms. Nancy E. Shire
Ms. Laurie Speight *
Ms. Elisabeth Twist

*Denotes those no longer with us
REMEMBERING OUR LOVED ONES

We remember the courage, strength, and remarkable spirits of those who lost their lives to ALS in 2017.

Ronald Adams
Frank Anderson
Pauline Anderson
Larry Atkins
Rick Baldwin
Raymond Baumgardner
Jeffrey Bernard
Roger Blain
Jeanne Bowe
Rose Burhoe
David Burns
Pamela Caldwell
Henry Cardwell
Karen Chase
Don Clark
Phil Coleman
Kevin Compton
Stanley Connett
Donna Conrad
Larry Cookus
Larry Corder
Darryl Crawford
Dylan Darling
Basilia De Vega
Otoniel Delgado
Davis Denny
Steven Dowell
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Mary Flynn
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Patricia Fritz
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Robert Gerl
Joy Getchell
Kathie Gregory
Jeanette Grindy

Jane Grover
Joseph Grumbles
Katherine Hall
Gregory Hamm
Prudence Hearn
Tomas Henningsgard
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George Wagner
Phyllis Walker
Janet Wardner
Judy Way

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Karen West
John Wiley
Sherry Williams
Joy Wyckoff
John Younie
Our Chapter provides support and resources for people living with ALS, their families, and caregivers living in the State of Oregon and the six counties of Southwest Washington.

**OUR MISSION**

To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

www.ALSOregon.org

For the online version of the Annual Report, please visit: bit.ly/ALSAnnualReport