



Humed Yusuf, Beaverton, OR
Read more on pg. 6

A MESSAGE FROM OUR EXECUTIVE DIRECTOR

Dear Friends,

ALS impacts all aspects of people's lives. Our organization strives to offer meaningful support that alleviates stress and offers practical help to families living with ALS. In 2022, we expanded our care services to offer more support to people living with ALS and their family members. First, we created an ALS-specific volunteer program that matches trained and vetted volunteers to families living with ALS to help with practical tasks and as peer mentors. Over-burdened family caregivers and people living with ALS can now receive more support through the coordination of vetted friends and family volunteers.

Already in the first few months of the new volunteer program, we've heard positive feedback. Debbie Lamedman of Tigard, Oregon shared, "Our volunteer is wonderful and generous with his time. The conversations he is able to have with my husband [living with ALS] make a world of difference with my husband's mood and overall sense of well-being. Their interaction is as important as medical visits. Maybe even more!" We look forward to sharing more with you about the support provided through this program next year.

In addition, we also expanded our existing bereavement services by adding a Bereavement Coordinator. Through this new position, we offer enhanced one-on-one grief support including online and in-person support groups for those who have lost a loved one to ALS. While we strive to find new treatments to stop ALS, we are committed to supporting families affected by ALS through their entire journey with the disease, including helping with grief and bereavement. These expanded care services have been made possible through the generosity of our giving community. Thank you!

Our community of friends and family who continue to give back also funded critical ALS research in 2022. We are encouraged by the addition of a new ALS treatment Relyvrio that is now available to all people with ALS. This new medication may slow ALS in some people by up to 20%. Your advocacy voices helped fast-track the FDA approval process to give people earlier access to this important treatment option. An amazing milestone for ALS research and advocacy!

I look forward to 2023 as our organization continues to work hard at supporting the lives of people living with ALS with these two innovative programs. We have a strong and robust care services team thanks to our donors and their loyalty to this mission. Together, we will find a cure for ALS.



Sincerely,

A handwritten signature in black ink that reads "Lance Christian". The signature is written in a cursive, flowing style.

Lance Christian, LMSW
Executive Director

NEW ALS MEDICATIONS IN 2022!

AMX0035 (Relyvrio) FDA Approved!

The U.S. Food and Drug Administration (FDA) approved AMX0035 for the treatment of ALS in September 2022. AMX0035 is designed to slow disease progression by slowing or preventing motor neuron cell death. Motor neurons are the cells that die in ALS. AMX0035 targets both the endoplasmic reticulum (ER) and mitochondria in ALS in motor neurons. This is important because the ER and mitochondria are connected (via mitochondrial membranes) and both play critical roles in maintaining neuron health and survival.

After almost three years of clinical trials in July 2020, the difference in survival between the AMX0035 group and the placebo group was evaluated. People with ALS who received AMX0035 lived an average of 6.5 months longer than the comparison placebo group. This data supported the FDA's decision to move forward with approval of the new medication.

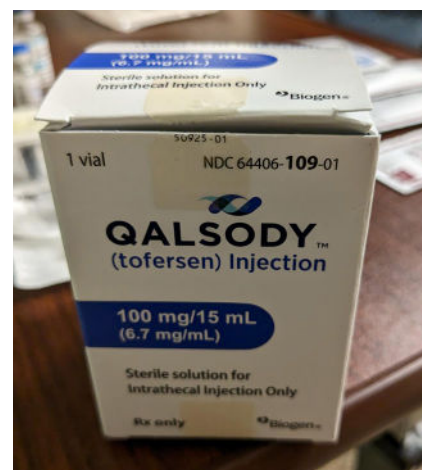
Steve Kowalski, who was diagnosed with ALS in 2017, testified twice before the FDA's advisory committee. "This is a positive step forward on that path to making ALS a livable disease until we find a cure. It means the possibility of increasing precious time with friends and family, greater independence and improving the quality of life for people living with ALS today."



Qalsody (Tofersen) FDA Approved!

This is the first treatment targeting a genetic cause of ALS - a mutation in the SOD1 gene. Tofersen was developed to specifically target the RNA produced from mutated SOD1 genes to stop toxic SOD1 proteins from being made. Tofersen was shown to reduce levels of the SOD1 protein in cerebral spinal fluid by 35% as early as eight weeks after participants began receiving the therapy.

To benefit from Tofersen, people with ALS must have a mutation in the SOD1 gene. People with ALS and their family members can receive genetic counselling and testing to see if they carry a genetic mutation linked to ALS.



**Research on
the Home Front**

PROVIDENCE
Brain and
Spine Institute

6 ALS Trials



OHSU
1 ALS Trial

2022 MARKED ADDITIONAL CARE SERVICES

Volunteer Program

Thanks to community support, we added a volunteer program to our suite of care services for families affected by ALS. There are two distinct avenues of service:



Caregiver Mentorship

Mentors offer empathy and solidarity as people who have “been there.” For caregivers, the best support often comes one-on-one from those who are on the same journey. Our Mentor Support Program connects those who are new to or currently serving as caregivers to former caregivers who have already lost a loved one that can share experiences and support.

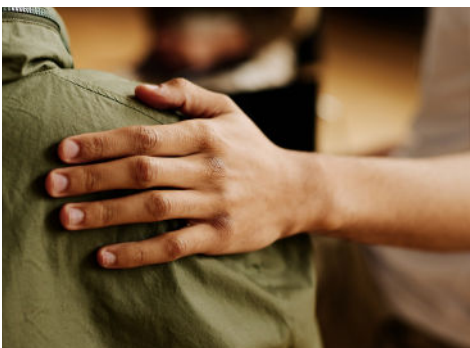


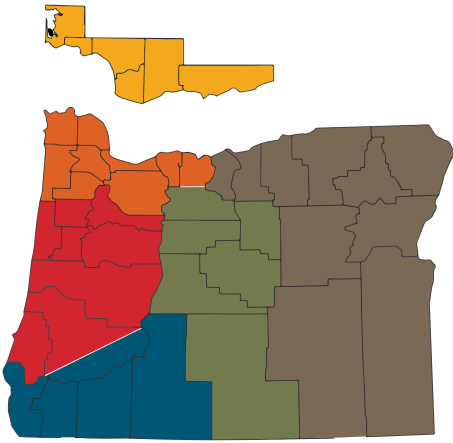
Helping Hands

The volunteer coordinator matches trained volunteers with individuals and families affected by ALS to assist with tasks like gardening, grocery shopping or errands – or offer companionship as a friendly visitor.

Bereavement Program (Expanded)

Support services from the chapter do not end with the loss of a loved one, and with the addition of a Bereavement Coordinator on staff there is now expanded access for one-on-one support, in-person grief support meetings, newsletter and additional online resources for those grieving.





WHO WE SERVED IN 2022

580 People Living with ALS

SIX REGIONS

- 253** Portland Metro
- 144** Willamette Valley
- 50** Southern Oregon
- 32** Central Oregon
- 10** Eastern Oregon
- 91** SW Washington

Pacific, Wahkiakum, Klickitat, Cowlitz, Clark, and Skamania Counties

340 Male
235 Female

5 individuals not identified or non-binary


66
Veterans Served

65
Average Age of Person Living with ALS


2-5 Years
Average Life Expectancy After Diagnosis

7%
People living with ALS given resources for children in their home


491
Caregivers and Families



- 49** attended caregiver bootcamp training
- 84** attended family day activities
- 29%** attend Caregiver Support Groups
- 154** supported by the Bereavement Program
- 24** Frontotemporal Dementia Support Groups Offered




CARE & SUPPORT SERVICES




356

Home visits for people living with ALS



32%

People with ALS provided communication and technology assistance



Support Communications
via Email, Phone, and Online with

5,411 People with ALS, caregivers, and family members

1,328 Healthcare professionals and community partners




43%

People with ALS supported with medical equipment



756


Total ALS Clinic Visits



414

Financial Assistance Grants Approves

\$169,671
Total Funds Awarded



188

Total Support Group Meetings

2022 SPECIAL EVENTS

It's amazing to see what we can accomplish when our community comes together. Through event contributions we provided care services to **580 people living with ALS** last year.



ALS Ski Event

Participants: 122

Fundraising Total: \$76,946



ALS Walk Events

Participants: 1,668

Fundraising Total: \$546,766



ALS Ride Event

Participants: 220

Fundraising Total: \$159,343



Together for ALS Gala

Participants: 343

Fundraising Total: \$343,743



ESSENTIAL ADAPTIVE COMMUNICATIONS TECHNOLOGY: SPOTLIGHT ON HUMED YUSUF

Humed Yusuf was born in Bangladesh and dreamed of moving to the US. He came to Kentucky for college and following school, explored New York, Wisconsin, and Oregon. “I think very few people are as fortunate as me, to be able to leave their home country and see the world.”

After obtaining a PhD in Physics, Humed succeeded as an engineer at Intel and contributed to the development of new microchips. Humed was then unfortunately diagnosed with ALS at the age of 34. He had to start giving up so many things, including his career at Intel. When the doctor delivered the news of his ALS diagnosis, Humed reflected, “It was like winning a very sad lottery.”

Humed has now been living with ALS for two years and he has lost many of his physical abilities, including the use of his hands. He was especially pained to lose the use of his phone – a critical tool in staying connected to his world and communicating with family and friends. Thankfully, the chapter’s Assistive Technology Services Coordinator, Ashley Loyning came to Humed’s home with a Speech-Generating Device equipped with eye-gaze technology. This device mounts to Humed’s power wheelchair and tracks his gaze, allowing him to access it hands-free - at no cost from the chapter.



This support technology enables Humed to stay connected while living with ALS: he uses it to write emails and text, communicate with his doctors, fill out financial documents, and play games like, Words with Friends. Ashley came to his home and taught him how to use it, and she continues to be a lifeline for Humed to ensure that this essential technology continues to work for him. In 2022, 32% of people living with ALS utilized our communication and technology assistance program.

Emotionally, Humed says he has been angry about his diagnosis, but knowing there is nothing he can do, he has resolved to be a ‘patient with patience’. Receiving a device that gives him back some abilities and independence completely free of charge, was vital for Humed’s quality of life in his ALS journey.

“A highlight of my role is supporting people living with ALS and their families to communicate despite the barriers. Communication is closely tied to identity and quality of life, and I feel honored I have the opportunity to help others access alternative methods of communicating while maintaining their independence, personal identity, and quality of life.”



Ashley Loyning

Assistive Technology Services Coordinator
ashley.loyning@alsoregon.org | 503-238-5559 x104

GRANT PARTNERS

Thank you to our foundation partners for their generous support of our chapter's work:

Ed & Romell Ackley Foundation

Carrico Family Foundation

Chambers Family Foundation

Chaney Family Foundation

Christopher and Dana Reeve Foundation

Coquille Tribal Community Fund

Cow Creek Umpqua Indian Foundation

DAV Charitable Service Trust

Marie Lamfrom Charitable Foundation

Reser Family Foundation

Salem Foundation

Spirit Mountain Community Fund

Three Rivers Foundation

Wildhorse Foundation

Wheeler Foundation



BOARD OF DIRECTORS

Amy Frazey – *President*

The Standard

Jason Drucker – *Vice President*

Foureyes

Katherine Hart – *Treasurer*

Agriculture Capital

Kevin Wright – *Secretary*

Travel Oregon

Ken Fink

Retired: Paralyzed Veterans of America

Arturo Gonzalez

Nike

Kim Goslin, MD, PhD

Retired: Providence Medical Center

Joe Gross

JGP Wealth Management

Diana Hendrickson

Corvallis Clinic

Tom Holt – *Past President*

The Holt Company, Government
& Public Affairs

Jim Lobdell

Retired: Portland General Electric

Doug McClure, PsyD

Licensed Psychologist

Ian McHone

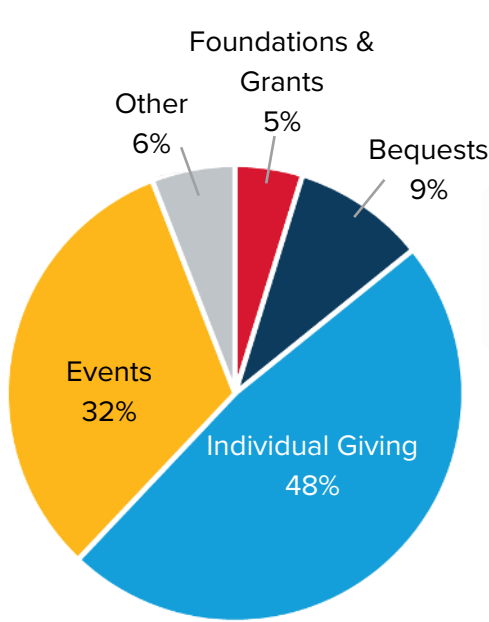
Retired: Tice Electric Company

Alan Teo, MD, MS

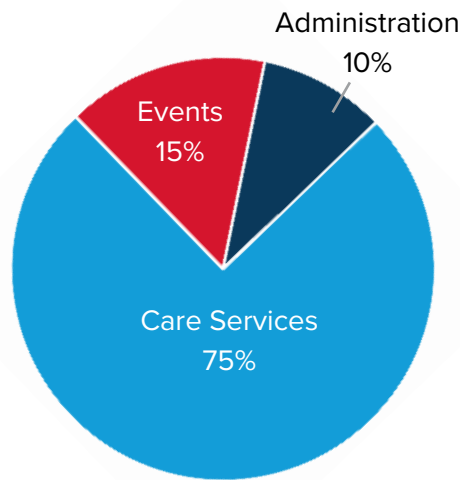
VA Portland Healthcare System and OHSU

Mark Turnbull

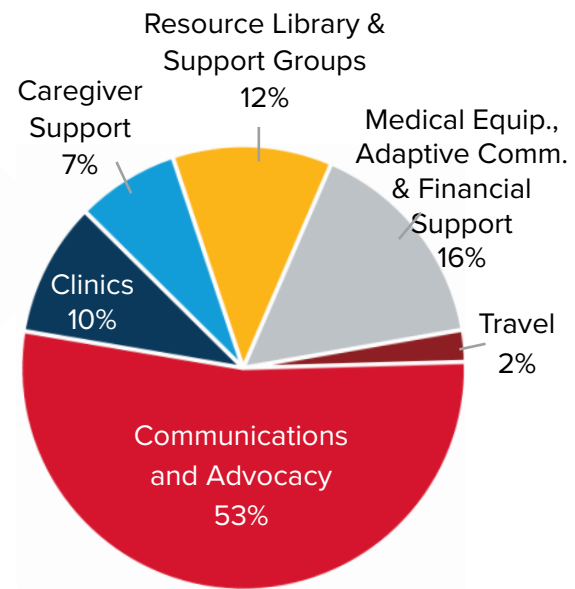
ComForCare of West Linn



REVENUE BREAKDOWN



BUDGET BREAKDOWN



PROGRAM SERVICES BREAKDOWN

STATEMENT OF FINANCIAL POSITION

Year ended January 31, 2023

ASSETS	2023
Cash and cash equivalents	\$1,369,820
Prepaid expenses	\$24,820
Revenue sharing refund receivable	-
Investments	\$2,918,804
Property and Equipment (net)	\$11,144
Total Assets	\$4,982,342
LIABILITIES AND NET ASSETS	
Accounts payable	\$212,763
Accrued payroll and related expenses	\$45,434
Refundable event deposits	\$ 45,209
Right of use liability	\$627,160
Refundable advance – Paycheck Protection Program	-
Total Liabilities	\$277,410
Net assets	
Without donor restrictions	
Board designated operating reserve	\$2,250,000
Undesignated	
Total net assets without donor restrictions	\$3,986,776
Total net assets	\$4,051,776
Total liabilities and net assets	\$4,982,342

STATEMENT OF ACTIVITIES

Year ended January 31, 2023

	2023
Revenues and other support	
Contributions	\$3,066,344
Grants and contracts	\$185,349
Paycheck Protection Program Grant	\$169,910
Special event revenue, less direct expense costs of \$29,159	\$207,721
Charitable Checkoff	\$36,282
Interest and dividends	\$59,625
Realized and unrealized gain (loss) on investments	\$215,850
Total revenues and other support	\$3,509,381
Expenses	
Program services	
Outreach and advocacy	\$1,127,643
Caregiver support	\$190,544
Education and support	\$315,259
Clinics	\$277,165
Independence programs	\$379,653
Total program services	\$2,290,264
Supporting services	
Management and general	\$508,634
Fundraising	\$321,142
Total expenses	\$3,120,040
Change in net assets	\$389,341
Net assets, beginning of year	\$3,662,435
Net assets, end of year	\$4,051,776

LEGACY SOCIETY MEMBERS

The Legacy Society forever honors those who have committed to a contribution to the chapter through their estate plans or will.

Angelene Adler-Ashkar
Mary Beth Baker
Jeff and Trina Bandelow
Samuel* and Pamela Beekman
Don and Heida Bruce
Anita and Dana Cadonau-Huseby
Lance Christian
Danny Collins*
Leonard Davis*
Barb Deeming
Kathleen “Kaye” Eberhard*
Ken and Tina Feldhaus
Amy and John Frazey
David Frost*
Sally Gehring
Kimberly Goslin, MD
Cynthia Greene*
Joseph Gross – In loving memory of my
mother, Helen Gross
Scott Hall*
Alexis V. Halmy
Katherine and Trevor Hart
Matson Haug* and Julie Isaacson*
Tom and Robin Holt
Karen Hughes
Dorothy Komarek*
Candace Kramer and Drew Prell

Debi and Randy Kyte*
Michael Lamont*
Jocelyn and Louis Libby, MD
James and Barbara Lobdell
Sherry Lougher
Steven Maxwell*
Aubrey M. McCauley
Doug and Claudia McClure
Leo and Dottie Mellon
Anne Moffett and Gordon Wright
Ralph and Susan Nicholson
Elinore Nudelman*
Justin Rubaloff
Teri and Steve* Sall
Patricia A. Schaffers
John Schaffers*
John and Barbara Seibert
Sharla Settlemier and David Cory*
Corliss Sherry – My heart, my love,
Clayton L. Sherry
Nancy Shire
Laurie Speight*
Darcy Thoulion
Elisabeth Twist
Laura Winterrowd
Stephen Zimmer
Jana R. Zvibleman

**Denotes those no longer with us*

**For more information visit alsoregon.org/ways-to-give/planned-giving
Contact: Amy Easton at 503-820-4525 or amy.easton@alsoregon.org**



“Becoming a member of Legacy Society was a no-brainer for me and my wife. I began seeing patients with ALS in the 1980s and taking care of ALS patients became a large part of my professional life as a pulmonary/critical care physician over time. When we began developing plans for when we die, we decided that contributing to ALS was a priority.

Once we decided that we wanted our chapter in our plan, it was pretty straight forward. And we learned that there are a number of ways to make it tax beneficial as well-an unexpected benefit.”- Lou Libby

REMEMBERING OUR LOVED ONES

*We remember the courage, strength, and remarkable spirits of those
who lost their lives to ALS in 2022*

James Anderson	Sally J. Black	Larry Wade	Christopher J. Evans
Harold Becker	Leslie Rainey	Brian L. Colson	Suzanne Y. Boyd
Gerald Laminen	Arthur K. Albright	Patrick Cosgrove	Brittany M. Ronhaar
Lucy A. Summers	Vickie Nelson	Greg Palmrose	William C. Rocker
Richard Dearborn	Paul E. Seble	Thomas Van Klaveren	Stephen E. Smith
Charles F. Keyes	Jeanette Wingate	James Geary	Jeanne Cutting
Alan W. Hash	Thomas E. Kuenzel	Laura D. Black	Donald Brown
Vivian D. Miller	Signe Patterson	Rondall M. Williams	Matthew Hobbs
Mark Freymuller	Theodore Lail	Ervin R. McLain	James Roberts
John McIndoo	Connie A. Thurber	Lisa Ditri	Steve Kennedy
Kevin E. Van Dyke	Christine Haworth	Shawn Lake	Molly J. McVey
Karen Morley-Smith	Barb McGibbon	Timothy Thomas	Donald Graham
Briant Regan	Mary K. Lekas	Marta Gavojdea	Catherine A. White
Kristi A. Johansen	David L. Sawyer	Patricia A. Phillips	Keith Birch
Fredric Layman	Andrea L. Northcote	Mydung A. Nguyen	David H. Flanders
Susan Jauron	Kayleen Tieman	Leland Johnson	Bernard Fitzpatrick
Holly D. Cohn	Jeffry J. Hunter	Christy M. Meisner	Jeanette A. Aronson
Greg Knudsen	Carolyn Saraceno	Lee Hall	Steven E. Dumont
Terri Murray	Clair Spicer	Larry Cole	Vannessa D. Hunt
Anne J. Nelson-Debord	Kevin Pardy	Michael P. Opton	Jon Carlson
Scott Powell	Jacqueline Meeds	Thomas Mills	Taffy L. Burrell
Ronald Buckmiller	Catherine E. Reisdorf	Laura E. White	Randy Mathewson
Giles R. Clay	Telesa Wilcock	Cherry Price	Gail Twiss
Patrick E. Geary	Adolfo C. Garcia	Willa Brooks	Teresa Delaney
Michael T. Larkins	Jane Cullinan	James D. Finch	Jean S. Cochran
Harold Olson	Milt Talbert	Christiana Hill-Fermo	Randall Wheatley
Vicki Houser	Barbara A. Cushing	Patrick Knight	Cynthia Kay
Bradley Morris	Rollo Wheeler	Mark Keene	Margaret J. Benson
Lora Stone- Mason	Kara Chytka	Nancy K. Anderson	Jani P. Aden
Norma Turner	Michael L. Oien	Corey Lauer	Stephen S. Rekow
Ricky Druby	Jerri Fredricks	Kristin Venderbush	Andrew Angus
Peter Parsons	Peggy McVitty	Richard Santee	Colton Allen
Michael T. Roelle	Theodore James	Vipin B. Vaidya	Norman L. Miller
Leonard Gover	Roberto Martinez	Brian C. Barreto	Willie F. Waterer
Niranjan Ramakrishnan	Stephen Sopocko	Ronald Schultz	Curtis D. McDaniel
Sharon Walton	Franchot Lytle	Janice McTaggart	Kathleen M. Grone
Samuel N. Beekman	Julie Le	Nicholas Natali	Stanley K. Heil
Glen Besenty	Jeanne E. Holloran	Mike M. Nixon	Douglas Remp
Michael Carroll	Truly Paollili	Matthew J. Adkins	
Kathryn I. Fanning	Janet I. Beutler	Jerome D. Daly	



2022 YEAR-ROUND PARTNERS



825 NE Multnomah St., Suite 940
Portland, OR 97232

ALSNorthwest.org | 503.238.5559