



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

2022 ANNUAL REPORT

ALS
ASSOCIATION

Oregon and
SW Washington
Chapter

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, slightly slanted 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.

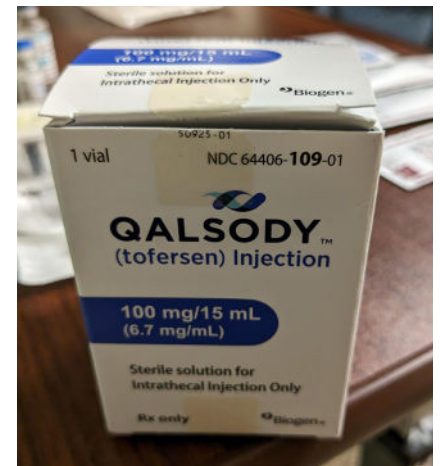
Steve Kowalski, who was diagnosed with ALS in 2017, testified twice before the FDA's advisory committee. "This is a positive step forward on that path to making ALS a livable disease until we find a cure. It means the possibility of increasing precious time with friends and family, greater independence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

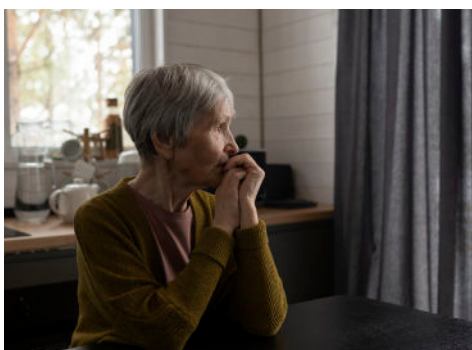
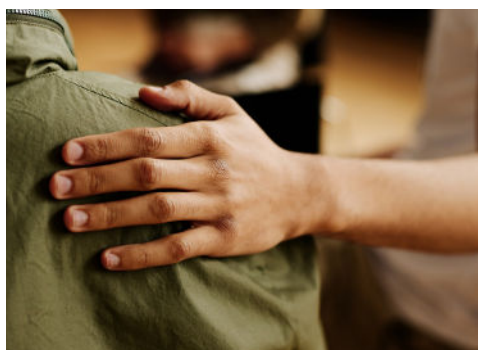


Helping Hands

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.

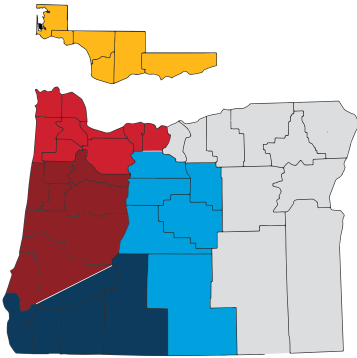
Bereavement Program (Expanded)

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

340
 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.



Ski to Defeat ALS

Participants: 122

Fundraising Total: \$76,946



Walk to Defeat ALS

Participants: 1,668

Fundraising Total: \$546,766



Ride to Defeat ALS

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



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Kevin Wright – *Secretary*
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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

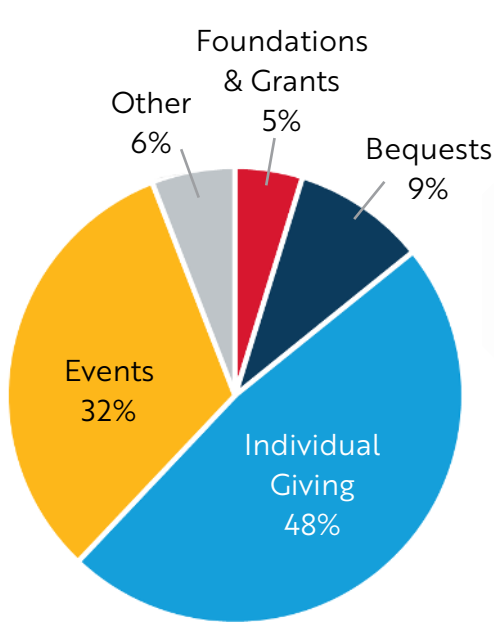
Jim Lobdell
Retired: Portland General Electric

Doug McClure, PsyD
Licensed Psychologist

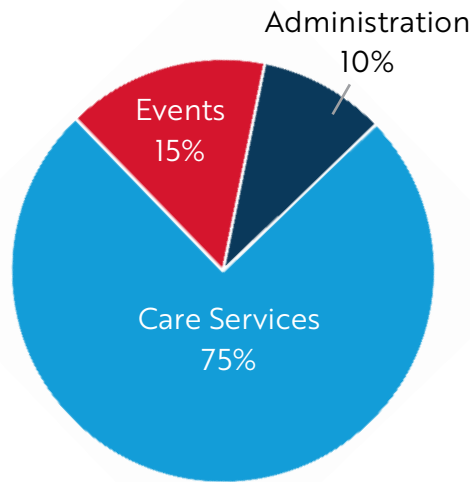
Ian McHone
Retired: Tice Electric Company

Alan Teo, MD, MS
VA Portland Healthcare System and OHSU

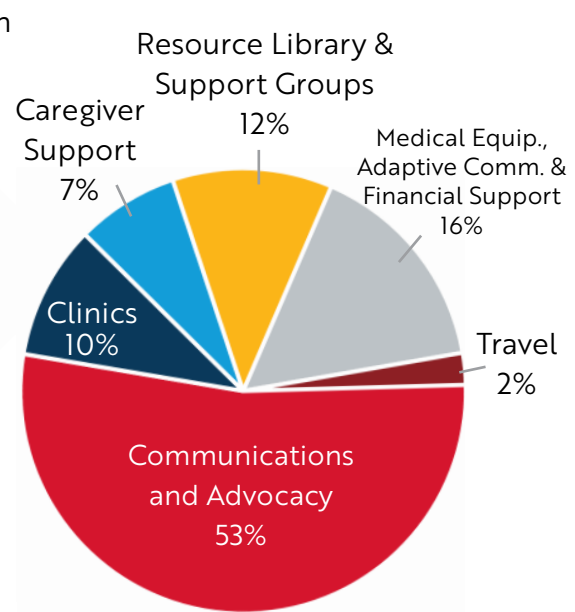
Mark Turnbull
ComForCare of West Linn



REVENUE BREAKDOWN



EXPENSE 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	Debi and Randy Kyte*
Mary Beth Baker	Michael Lamont*
Jeff and Trina Bandelow	Jocelyn and Louis Libby, MD
Samuel* and Pamela Beekman	James and Barbara Lobdell
Don and Heida Bruce	Sherry Lougher
Anita and Dana Cadonau-Huseby	Steven Maxwell*
Lance Christian	Aubrey M. McCauley
Danny Collins*	Doug and Claudia McClure
Leonard Davis*	Leo and Dottie Mellon
Barb Deeming	Anne Moffett and Gordon Wright
Kathleen "Kaye" Eberhard*	Ralph and Susan Nicholson
Ken and Tina Feldhaus	Elinore Nudelman*
Amy and John Frazey	Justin Rubaloff
David Frost*	Teri and Steve* Sall
Sally Gehring	Patricia A. Schaffers
Kimberly Goslin, MD	John Schaffers*
Cynthia Greene*	John and Barbara Seibert
Joseph Gross – <i>In loving memory of my mother, Helen Gross</i>	Sharla Settlemier and David Cory*
Scott Hall*	Corliss Sherry – <i>My heart, my love, Clayton L. Sherry</i>
Alexis V. Halmy	Nancy Shire
Katherine and Trevor Hart	Laurie Speight*
Matson Haug* and Julie Isaacson*	Darcy Thoulion
Tom and Robin Holt	Elisabeth Twist
Karen Hughes	Laura Winterrowd
Dorothy Komarek*	Stephen Zimmer
Candace Kramer and Drew Prell	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
Harold Becker
Gerald Laminen
Lucy A. Summers
Richard Dearborn
Charles F. Keyes
Alan W. Hash
Vivian D. Miller
Mark Freymuller
John McIndoo
Kevin E. Van Dyke
Karen Morley-Smith
Briant Regan
Kristi A. Johansen
Fredric Layman
Susan Jauron
Holly D. Cohn
Greg Knudsen
Terri Murray
Anne J. Nelson-Debord
Scott Powell
Ronald Buckmiller
Giles R. Clay
Patrick E. Geary
Michael T. Larkins
Harold Olson
Vicki Houser
Bradley Morris
Lora Stone- Mason
Norma Turner
Ricky Druby
Peter Parsons
Michael T. Roelle
Leonard Gover
Niranjan Ramakrishnan
Sharon Walton
Samuel N. Beekman
Glen Besenty
Michael Carroll
Kathryn I. Fanning

Sally J. Black
Leslie Rainey
Arthur K. Albright
Vickie Nelson
Paul E. Seble
Jeanette Wingate
Thomas E. Kuenzel
Signe Patterson
Theodore Lail
Connie A. Thurber
Christine Haworth
Barb McGibbon
Mary K. Lekas
David L. Sawyer
Andrea L. Northcote
Kayleen Tieman
Jeffry J. Hunter
Carolyn Saraceno
Clair Spicer
Kevin Pardy
Jacqueline Meeds
Catherine E. Reisdorf
Telesa Wilcock
Adolfo C. Garcia
Jane Cullinan
Milt Talbert
Barbara A. Cushing
Rollo Wheeler
Kara Chytka
Michael L. Oien
Jerri Fredricks
Peggy McVitty
Theodore James
Roberto Martinez
Stephen Sopocko
Franchot Lytle
Julie Le
Jeanne E. Holloran
Truly Paollili
Janet I. Beutler

Larry Wade
Brian L. Colson
Patrick Cosgrove
Greg Palmrose
Thomas Van Klaveren
James Geary
Laura D. Black
Rondall M. Williams
Ervin R. McLain
Lisa Ditri
Shawn Lake
Timothy Thomas
Marta Gavojdea
Patricia A. Phillips
Mydung A. Nguyen
Leland Johnson
Christy M. Meisner
Lee Hall
Larry Cole
Michael P. Opton
Thomas Mills
Laura E. White
Cherry Price
Willa Brooks
James D. Finch
Christiana Hill-Fermo
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Mark Keene
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Corey Lauer
Kristin Venderbush
Richard Santee
Vipin B. Vaidya
Brian C. Barreto
Ronald Schultz
Janice McTaggart
Nicholas Natali
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Jerome D. Daly

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Suzanne Y. Boyd
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Jani P. Aden
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Colton Allen
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Willie F. Waterer
Curtis D. McDaniel
Kathleen M. Grone
Stanley K. Heil
Douglas Remp





2022 YEAR-ROUND PARTNERS



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

ALSOregon.org | 503.238.5559