



The Chapter-Link

January 2024

1170 Old Henderson Rd, Suite 221
Columbus, OH 43220
614-273-2572
or toll free
866-273-2572
www.alsohio.org

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* * *

Save the Date

Columbus Blue Jackets

January 19th

Nationwide Arena

7:00 pm

(See page 2 7)

New Year's Resolutions

Our new identity as ALS United Central & Southern Ohio has renewed our focus on the priorities that will best help our local families living with ALS. The New Year is the perfect time to affirm our commitments to you and share some of our goals and aspirations for 2024 and beyond. These are our New Year's Resolutions – to you.

We resolve to...

Serve more ALS families. We are no longer constrained by our original 55-county boundary. We've long been serving people in southeast Indiana and northern Kentucky through Clinic services and support groups. Because of recent state funding, we are now able to invest more resources into our programs and begin providing a greater degree of service to the rising number of people diagnosed with ALS regardless of where they live.

Directly fund research for treatments and a cure. We are now able to direct research contributions that come to our organization, and our board is finalizing plans and policies to do just that. Did you know that there are numerous ALS research projects right here in Ohio? We are learning more about these projects and their researchers so that we may invest our research dollars for the greatest impact across the nation. We will share the details once the new research funding policies are approved.

Expand access to equipment and supplies. We are refining our equipment programs to bring more items to people with ALS than ever before. The loan program continues to be the bedrock of our equipment service, and in addition we are greatly expanding purchases of single-use items and adaptive devices. We have also removed the limit of items per person, so now people with ALS can get more of what they need.

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Develop deeper relationships with our Multidisciplinary Clinic partners. We are looking for additional ways to be of service to our longstanding clinic partners at OhioHealth and University of Cincinnati. In addition, we are developing new and enhanced relationships with clinicians and teams at The Ohio State University Wexner Medical Center, the Dayton VA, and Dayton neurologists looking to focus on clinical ALS management and care. VA.

Grow ALS community connections. By enhancing and strengthening our Support Groups, Education & Exchange groups, and social/awareness events, we are striving to bring people and families living with ALS closer together for mutual support and friendship. There is strength in community.

Connect with neurologists throughout the state. We are endeavoring to bring greater awareness of ALS, multidisciplinary clinics, and our services to neurologists across the state. Our goal is to help them recognize signs of ALS and make referrals to ALS specialists sooner, leading to earlier diagnoses and increased eligibility of patients to participate in clinical trials.

Increase ALS awareness to heighten urgency for a cure. We will work toward this by bringing greater awareness of ALS to healthcare professionals, legislators, and the public – and advocating with state and federal government for funding, access to treatments, and policies that improve quality of life for people with ALS.



New & Improved Chapter Link Newsletter Coming February 2024

Last year we surveyed readers of the Chapter Link. This year we've recreated ourselves as an independent organization. Now, get ready for a new monthly newsletter – launching next month!

The Chapter Link will have a new name, a fresh look, and feature the latest content to keep you informed about what's happening for you locally, and what's new in the world of ALS research and care. Be on the lookout for it, and let us know what you think!

RESEARCH UPDATES

PrimeC Safe, Shows Trends Toward Slowing ALS Progression: Trial Data

Positive findings from PARADIGM support launch of pivotal trial in 2024
by *Margarida Maia, PhD* | December 12, 2023 - Originally posted on ALSnewstoday.com

NeuroSense Therapeutics' PrimeC was found to be safe and well tolerated in a Phase 2b trial, and use of the oral therapy for six months led to “meaningful slowing of disease progression” in people with amyotrophic lateral sclerosis (ALS), the company said in a [press release](#) announcing top-line results.

The new data comes from [PARADIGM \(NCT05357950\)](#), a fully enrolled clinical trial that's testing PrimeC against a placebo in 69 adults with a diagnosis of ALS.

The positive findings will now support the launch of a pivotal and global Phase 3 trial that's planned for 2024. The U.S. Food and Drug Administration (FDA) already has agreed to the manufacturing practices and product specifications set in place ahead of the trial.

“The release of this portion of the top-line results of the PARADIGM trial marks an exciting milestone for NeuroSense as we take another step toward helping people suffering from this dire disease,” said Alon Ben-Noon, NeuroSense's CEO.

According to the release, PrimeC “achieved primary safety and tolerability endpoints [goals] with a safety and tolerability profile comparable to [a] placebo.”

Use of PrimeC in PARADIGM leads to 29% slower disease progression

NeuroSense also is planning to report the results of biomarker analyses from the PARADIGM trial in the first half of 2024.

These include changes in ALS blood biomarkers TDP-43 and prostaglandin J2 after six months — one of the trial's main goal. The company also expects to share its findings on changes in neurofilament blood levels, a biomarker of nerve cell damage. That analysis is being done in collaboration with Biogen.

“We look forward to meeting with the FDA to determine the best path forward and to advancing discussions with strategic partners who share our vision for PrimeC to benefit people living with ALS,” Ben-Noon said.

PrimeC contains a fixed-dose combination of two FDA-approved medications: ciprofloxacin, an antibiotic used to treat bacterial infection, and celecoxib, a medicine for relieving pain and inflammation. It is expected to slow disease progression by blocking key mechanisms behind ALS.

PARADIGM, slated for completion in fall of 2024, is testing a long-acting formulation of PrimeC, which releases the medications in the body over time. In the trial, PrimeC was given at a total daily dose of 1,496 mg, taken as two tablets twice daily.

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RESEARCH UPDATES

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PARADIGM, slated for completion in fall of 2024, is testing a long-acting formulation of PrimeC, which releases the medications in the body over time. In the trial, PrimeC was given at a total daily dose of 1,496 mg, taken as two tablets twice daily.

A total of 69 adults with ALS — taking part in the study at sites in Canada, Italy, and Israel — were randomly assigned to receive the medication or a placebo for six months. Data was gathered from 68 patients, due to one misdiagnosis.

The trial's main goals are to determine if PrimeC is safe and well tolerated in ALS patients, and whether it reduces the amount of ALS biomarkers in circulation, indicating a potential effect on disease processes.

Secondary measures include changes in the ability to perform daily tasks, as assessed with the ALS Functional Rating Scale-Revised (ALSFRS-R), as well as changes in lung function, quality of life, and survival.

Over the trial's six months, safety and tolerability profile of PrimeC was comparable to that of the placebo.

Also, patients treated with PrimeC experienced a 29% slower disease progression on the ALSFRS-R scale, as well as a 13% slower decline in lung function, compared with those given a placebo. These differences failed to reach statistical significance, but the company noted that this trial was not powered to detect such significant difference.

“In addition to the safety and tolerability profile observed, we believe the 29% difference observed in ALSFRS-R in favor of PrimeC as well as the 13% decline in [lung function] compared to the placebo arm, illustrate PrimeC's potential to render a meaningful clinical benefit to people living with ALS,” said Ferenc Tracik, MD, NeuroSense's chief medical officer.

After completing the six months of dosing, most participants (96%) chose to enter an open-label extension, in which all are being treated with PrimeC for up to one year. So far, all who completed 1.5 years of treatment have opted to continue taking PrimeC by joining an ongoing investigator-initiated trial.

“I am excited by the top-line clinical data from PARADIGM, as this is an important milestone for the patients I care for and for the entire ALS community,” said Merit Cudkowicz, MD, chair of neurology at the Massachusetts General Hospital and director of the Healey & AMG Center for ALS in Boston.

“The positive results support moving forward to a Phase 3 pivotal trial. The biomarker data will also be very informative, and I look forward to seeing those results in early 2024,” added Cudkowicz, who is also a member of NeuroSense's scientific advisory board.

UPDATES

January Virtual Education & Exchange Group Meeting

"Never lose touch" - How using your iPhone can improve quality of life even if you lose the ability to hold and touch it.

ALS United is thrilled to welcome Tom Meadows to present on **Steve's Way** at our organization-wide Virtual Education & Exchange Group Meeting on Monday, January 22 at 6:30pm. Steve's Way is an awareness campaign founded by Tom Meadows to educate people about hidden and undocumented functionality in the Apple OS that can specifically benefit people with ALS.

Tom's presentation will provide an overview of all the capabilities hidden on smartphones, and he will share his vision of what is coming soon from iPhones and Androids. Tom is a retired software entrepreneur who has built and sold companies for over 100 million dollars, and in the process created numerous jobs along the way.

About Steve's Way

Tom's childhood friend, Steve, was diagnosed with ALS in 2021. Tom became his accessibility partner: helping him find ways to continue to communicate and access his technology during the different stages of ALS progression. Together they found multiple solutions that would allow Steve to continue to use his iPhone. After his passing, Tom got curious about what else might be possible for people like his friend. He discovered additional iPhone accessibility solutions that could be adopted as symptoms dictated.

Tom uncovered functionality that most people don't know about, including:

- Voice Control - navigating your iPhone using solely your voice.
- Mouse Control - navigating your iPhone using a standard Bluetooth mouse.
- Head Tracking - using head movement to move the cursor, and facial gestures, sounds or switches to 'tap.'

Tom developed the Steve's Way kit that contains tools that someone with ALS would need for iPhone access regardless of how their ALS symptoms unfold. This kit has allowed Tom to help people turn on the accessibility features using Zoom. Tom has shipped over 600 free kits and has many more kits to send out.

To register and receive your kit, please go to the following website - www.stevesway.com



COMMUNITY OUTREACH & CHAPTER EVENTS

Last Call for 2023 Quality of Life Reimbursement Grants

Reimbursement Request Deadline January 14, 2024

Reimbursement requests for 2023 will be taken until January 14, 2024, or until Grant funds are depleted. We can reimburse individuals through our Quality of Life Reimbursement Grant up to \$1,200 in eligible expenses to individuals who qualify.

You can find out if you qualify for the Grant and download the necessary application on our website at <https://alsohio.org/patient-grants>.

For more information or for a hard copy grant packet, please contact Carleen Hubbell, Care Services Coordinator, at (614) 273-2572 x110, or chubbell@ALSohio.org

Changes to Equipment & Supply Donation Acceptance

Thank you for considering us for your equipment and supply donations.

We appreciate each donation that we receive, and our goal is to get it back out into our ALS population to be used again. However, due to storage space limitations, sanitization challenges and other considerations, we cannot accept every donation.

Please note that we are no longer accepting walk-in donations without prior approval. Please contact Sage Brand, Program Services Coordinator, to see if your donation can be accepted. She will work with you to facilitate the donation or provide you with other options.

pALS-to-pALS Equipment & Supply Exchange

If we cannot accept your donation, you may also make your item available for free directly to other people with ALS through our pALS-to-pALS Equipment & Supply Exchange. These are advertised through Free Fridays emails to all people with ALS who are registered with us. *Free Fridays will not run on Holidays or if the office is closed.*

This program allows individuals with equipment and supplies they no longer need to give away those items to others that need them. Please note that these donations from one person to another are not tax deductible.

If you have free supplies or equipment, contact Sage Brand, Program Services Coordinator, **by each Friday at 2 pm.** Give a description of the equipment you want to donate, maybe photos, and an email or phone number that she can share in this weekly (Friday) email notification. Please also email what county or city you reside in. Let Sage know if you want your item(s) relisted, or it may be deleted if you do not update its status.

You can reach Sage at sbrand@ALSohio.org or at the office: (866) 273-2572 x107 or (614) 273-2572 x107.

COMMUNITY OUTREACH & CHAPTER EVENTS

Cello Recital Raises Awareness and Funds

Matt Moritz graduated from The Ohio State University in 2021 with a bachelor's degree in neuroscience. He also enjoys playing the cello. On December 2 in Columbus, Matt combined these two passions by holding a cello recital benefiting ALS United Central & Southern Ohio.

His program featured music by composers who lived with a movement-related disease or disorder. Casey Cook accompanied Matt on piano, and Sam Johnson joined him on cello. Matt invited Melissa Dardinger of ALS United Central & Southern Ohio to provide the audience with an overview of ALS and what we're doing to fight it. Admission was free, and donations were encouraged. So far, his fundraiser has brought in more than \$1,200 to fight ALS. Thank you, Matt!



**COLUMBUS BLUE JACKETS
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FRI | JAN 19 | 7:00PM

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**Purchase your tickets at
<http://bluejackets.com/ALS>**

REMEMBERING

Cincinnati Area	Columbus Area	Dayton Area	Lima Area
	Enno "John" Raab 12/10/23	William Shebetka 12-16-23	
	David Schrider 10-26-23		

FOR SALE

2019 Chrysler Pacifica Braunability Van (5/24) Lowered floor, power door, power folding ramp, power kneeling system, remote entry, step & roll passenger front seat. Price is negotiable. Mileage is 13,052. If interested, please **Contact Hildaliz Bridges at 513-850-4225 or email: hildalizcolon@icloud.com**

Invacare Carroll CS7 Hi-Low Hospital Bed (3/24) 36" width with side rails, asking \$1500 or best offer.
Prius Rythm Multi Mattress 36" width, asking \$1500 or best offer. These items are located in Loveland.
Please contact Sean Waugh at 765-490-4578 for inquiries.

2009 Gold Toyota Sienna XLE Braun Rampvan. Has 144,310 miles, a ramp, four anchors, and straps to accommodate a power wheelchair. Can also seat 4 additional passengers plus driver. Front seats formatted to remove for wheelchair access. Van was just serviced and in good working condition. Minor cosmetic issues but runs smoothly and has been reliable. Asking \$10,000 OBO. **Contact Zoe Dennhardt at 937-760-5596 serious inquiries only.**

Wheelchair Lift - RAM Trus-T-Lift Vertical Platform Lift. Indoor or garage. Capacity 750 lbs. Travel height up to 28". Aluminum platform is 48" x 60" with 35" railings, configured as enter then exit right at 90 degrees (can be reconfigured). Lift is 36" x 54" with 42" sides and automatic folding 8" ramp, and has Up/Down soft touch paddle controls plus emergency stop in lift, with remote call button. Used in garage for motorized wheelchair to travel to main level. Like new. Asking \$2,000. **Contact Richard at 513-967-7550 or rcfiddes@fuse.net.**

2008 Chrysler Town & Country Handicap Van (1/24) Owned since January of 2023, Purchased with 86,049 original miles on it and only driven a very few hundred miles; the mileage is still 86,000+. Excellent running condition. Van has been detailed; looks and smells great. We bought it from a family who had just lost a member to ALS. They sold it to us at a reduced cost -- paying it forward -- and that is our intention. We have \$14,000 in it and we are asking \$14,000. We are not trying to make a profit, and neither did the two previous ALS families. **Please contact Russell by phone at 513-518-7537 OR email rdahlem40@yahoo.com**

. . . . For Sale Ads continued on page 9

FOR SALE

Permobil Corpus F3 Electric Chair (1/24) original list price was \$73,000. Never used, Chair does everything; loaded w/many features. Purchased from another family who had ALS for \$1000 .Asking price is \$1,000 for anyone who has ALS. **Please Contact: Dennis for more detailed information at 419-234-2342**

2009 Ford Econoline full-sized van (1/24) - Mileage is 88,500, Black & tan exterior; tan interior, Hydraulic Braunability fully automated lift; works great. We purchased this certified van from MobilityWork in February of this year for \$34,990 and only put 1200 miles on it. Works and runs great. Has full set of tie downs for a wheelchair. Asking \$27,000 or best offer – located in Lebanon, Ohio. If interested, please **Contact Kathy at 513.850.9464 or kathy.edwards08@gmail.com**

2017 Toyota Sienna SE VMI Northstar handicapped Accessible Van (12/23) Wheelchair accessible conversion van for ingress/egress- includes: side entry in-floor power ramp, rear passenger kneeling system, remote access to operate power sliding door/ramp/kneeling functions, interior access switches, 4-point wheelchair tie down system, EZ Lock BL-6290 Docking System. Front passenger seat included. Single owner, non-smoking, Silver exterior, leather interior, heated front seats, touch display, Bluetooth, GPS navigation, moonroof, back up camera, very clean/good condition. Selling for \$55,000 OBO
Contact Laura Trapp at letrapp27@gmail.com or 513-314-6126

2019 Permobil Corpus M3 Mobility Vehicle Electric Wheelchair (12/23) Black. \$3,000 Adjustable footrest & height, elevated legrest, flip up padded armrest, attendant joystick, reclining, tilt in space, I-drive software included, hip & elbow guards included and much, much more. **Phillips Respironic Cough Assist—Never Used.** \$1,500 Comes w/power cord/facemask/tubing.
Please Contact Lee for more product features at 419-348-5908

MOLIFT Duo 2 Post Rails System & Air Bundle Kit (12/23) used for less than 2 weeks, Asking \$3,200 located in Putnam County. If interested, please **Contact: Mary Ann at 419-234-3837**

Hill ROM Care Assist ES Hospital Bed (12/23) with Prius Rhythm multi- alternating, low air loss, pressure relief system with lateral rotation-\$2,500 **Adjustable Hospital Table-\$50** **Combination Commode/Shower Chair-\$200** **Wheelchair Ramp & Platform,** 2- 3 ft sections, 2- 8 ft sections, 1- 5x5 platform, 1 rail and 4 risers . Ramp has been disassembled and ready to move.. \$1,800 If interested, please **Contact: Jenniffer Acton at 513-404-4123 or jacton3695@gmail.com** Please leave message.

Quantum Q6 Edge powered wheelchair (12/23) with TRU-Balance, 3 power positioning. Drive wheels 14" solid, caster wheels, front and rear 6"solid. Maximum speed up to 5mph, turning radius 20". Overall length 35.5" without foot riggings, base width 24". Weight capacity 300lbs. Jay Union Cushion seating. Asking \$3,000. Free delivery within Ohio and surrounding states. For more information or photos, please **Contact: Gemma Hatoum @937-689-3234 or e-mail at gh200001@hotmail.com**

Invacare Hydraulic Lift Model 9805P (12/23) Comes with a body sling. 450 lbs. weight capacity. For all specs, google make & model, Asking \$400. Retail for \$580 with sling. Basically new, only used 3 times. **Invacare Tracer Sx5 Wheelchair Recliner** Brand new; never used. Has desk length arms and T94HCP hemi elevating leg rests, 18" seat width, tall back, and padded calf pads. For all specs, google make & above description, Asking \$350. Retail online for \$492. If interested in either item, **please contact Tara at (740) 606-6033 or tara15935@gmail.com**

Caregiver & Survivor Groups

<p>CINCINNATI CAREGIVER GROUP (current caregivers only)</p>	<p>Tuesday January 23, 2024 1:00—2:30 pm</p>	<p>Open Discussion</p>	<p>Yvonne Dressman, LSW</p>	<p>The Good Shepherd Lutheran Church 7701 Kenwood Rd Cincinnati, OH 45236</p>
<p>CENTRAL OHIO CAREGIVER GROUP AND GREATER DAYTON MIAMI VALLEY-CAREGIVER GROUP (current caregivers only)</p>	<p>Monday January 15, 2024 1:00—2:30 pm</p>	<p>Respiratory Therapy & ALS Trevor Aldelsberger, RT</p>	<p>Carleen Hubbell, BS, MA Melinda McGuire, RN</p>	<p>Attend <i>Virtually or In-Person</i> Dempsey Family Education & Resource Center, Riverside Hospital 3535 Olentangy River Rd, Columbus 43214 https://ohiohealth.webex.com/join/dempseycenter Meeting Access Code 736 294 987 Or WebEx call-in dial: # 650-479-3208 Meeting Access Code: 736294987</p>
<p>CENTRAL OHIO SURVIVOR GROUP</p>	<p>No Group This Month</p>	<p>A social lunch to enjoy the company of those who have experienced a loss to ALS (Lunch is on your own)</p>	<p>RSVP necessary by Friday, May 12th to Carleen Hubbell chubbell@alsohio.org</p>	<p>TEMPORARY <i>New Venue</i> Sunny Street Café 4733 Reed Road Columbus, OH 43220</p>
<p>CINCINNATI AREA SURVIVOR GROUP</p>	<p>No Group This Month</p>	<p>A social dinner to enjoy the company of those who have experienced a loss to ALS (Dinner on your own)</p>	<p>Host: Mary Naylor *Please RSVP to Mary Naylor at 513-891-1475</p>	<p>Slatts Pub 4858 Cooper Road Cincinnati, Ohio 45242 (Private Dining Room)</p>
<p>GREATER DAYTON IN-PERSON SURVIVORS GROUP</p>	<p>No Group This Month</p>	<p>Our Survivors Group is a social dinner to enjoy the company of friends who have experi- enced loss to ALS- to stay connected with peers & our Chapter. <i>Dinner on Your Own</i></p>	<p>Facilitators Melinda McGuire Mary Helme Claire Robbins Bob Westendorf</p>	<p>Rusty Bucket Restaurant & Tavern 2812 Miamisburg-Centerville Rd Dayton, OH 45459 We will meet in Private Room Ask for ALS United when you arrive **Must RSVP to your area Dayton Care Coordinator**</p>

ALS United Central & Southern Ohio Chapter-Wide Education and Exchange Groups

DATE	TOPIC	LOG-IN/CALL-IN INFORMATION
<p>Monday January 8, 2024 6:00 pm—8:00 pm Facilitator: Yvonne Dressman</p>	<p>CINCINNATI REGIONAL AREA “Respiratory Care 101” Ann Compton, ALS Clinic RT Sue Morrison, Global Medical RT</p>	<p>In-Person Support Group The Good Shepherd Lutheran Church 7701 Kenwood Rd Cincinnati, OH 45236</p>
<p>Monday January 8, 2024 6:30 pm –8:30 pm Facilitator: Carleen Hubbell</p>	<p>COLUMBUS REGIONAL AREA “Smart Home & Equipment Programs Through ALS United” Sage Brand, MSW Equipment Coordinator ALS United Central & Southern Ohio</p>	<p>In-Person Meeting McConnell Heart Health Center 3773 Olentangy River Road Columbus, OH 43214 Classroom 1—Main Floor</p>
<p>Monday January 15, 2024 6:30pm—8:30 pm Facilitators: Melinda McGuire</p>	<p>GREATER DAYTON/MIAMI VALLEY REGION “Benefits of Music Therapy” Megan Carlson University of Dayton Music Therapy Club</p>	<p>In-Person Meeting Austin Trace Health and Rehab 250 W Social Row Road Washington Township, OH 45458</p>
<p>Monday January 22, 2024 6: 30 pm–8:30 pm</p>	<p>CHAPTERWIDE VIRTUAL ALS United Central & Southern Ohio E&E Meeting Steve’s Way—“Never Lose Touch” - “How using your iPhone can improve quality of life even if you lose the ability to hold and touch” Tom Meadows, retired software entrepreneur & founder of “Steve’s Way”</p>	<p>Virtual Only Join Zoom Meeting https://zoom.us/j/93106654847 Meeting ID: 931 0665 4847 OR CALL IN . . *+1 309 205 3325 US *+1 312 625 6799 US (Chicago)</p>

Inclement Weather Announcement

It is that time of year when bad weather can affect Support Group meetings. Every attempt is made to report cancellations in a timely manner but winter weather can be unpredictable. Below is our procedure for providing information regarding changes or cancellations for your area support group. Time Permitting - Any cancellations or changes in Support Group meetings will be posted on our website - alsohio.org You may call the Columbus office at (614) 273- 2572 or (866) 273-2572 between the hours of 9:30am and 3:30pm Monday through Friday. The Care Service Coordinator for your area will put a message on their phone if there are changes or cancellations. The Care Service Coordinators will send an e-mail to all known attendees if there are changes or cancellations. You are encouraged to have your email on file with our office. Please remember that road conditions can vary by location. You are advised to carefully consider the importance of your safety versus attendance at support group. Your well-being is our primary concern.

REMINDERS

Monthly Chapter-Link Newsletter Mailings

The Chapter-Link is mailed to all patients who are registered with us. When individuals are no longer actively receiving our services, they are removed from the newsletter mailing list. Former caregivers and interested parties are encouraged to continue receiving the newsletter by email. Newsletters dating back to one year from the current issue area available at <https://alsohio.org/navigating-als/resources>.

National ALS Registry – Sign Up Today

**The National ALS Registry is the single largest ALS research project ever created and is designed to identify ALS cases 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* – help us find a cure, sign up today! www.cdc.gov/als

Remembering Your Loved One Through a Memorial Gift

Losing someone to ALS is something that no one wants to experience. But many, through the frustration and pain, find a way to give back and honor their loved one. Your friends and family can help continue providing services for those still living with ALS by making a donation to our organization in memory of their loved one. This can be done by naming us in your loved one's obituary: Memorial donations may be made to ALS United Central & Southern Ohio, 1170 Old Henderson Rd., Ste. 221, Columbus OH 43220. We send thank you letters to all donors and acknowledgment to the family listing the names only (amount is not listed) of those who have made donations.

Attention Veterans

If you are a veteran with ALS or the spouse of a deceased veteran who had ALS, please contact the ALS United Central & Southern Ohio office (614-273-2572 or toll free 866-273-2572) for information on the Veterans Administration disability compensation program. Valuable resources can also be found on our website, <https://alsohio.org/navigating-als/resources-for-military-veterans>.

ALS Information for Kids and Teens

We are very grateful to The Marion Community Foundation - Spencer Stephens Fund for continuing support of a program benefiting the children and teens of our PALS. The Spencer Stephens' Flamingo Backpack Project is patterned after a program created by Deborah Feigenbaum, a clinical social worker with ALS Connecticut. Working from this model, we developed a backpack with informational and fun resources to help kids cope with a having a parent or family member with ALS. Initially designed to provide ALS resources for children ages 6 to 12 years old, the project was expanded to include a teen version of the backpack and an outreach program for children under six. If you know of children or teens who could benefit from an ALS information packet (some limitations apply), please call Care Services (866) 273- 2572. Learn more at <https://alsohio.org/resources-for-children-and-teens>.



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 Sharonville, OH 45241
 513-686-1151



**PLAN FOR TOMORROW,
 LIVE FOR TODAY.**



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Our monthly newsletter includes ads from companies that are actively involved in services to the ALS community. We grateful to these friends not only for their support of ALS United Central & Southern Ohio, but also for the long-standing services and products that they provide to persons with ALS (PALS). We appreciate our relationship with these companies and are fortunate to have them as associates in providing quality care for PALS.



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