



# The Chapter-Link

## April 2023

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 Dates 2023



**Columbus Walk**  
Sunday, September 10<sup>th</sup>  
Coffman Park Pavilion  
Dublin OH 43017

\* \* \*

**Cincinnati Walk**  
Sunday, September 17<sup>th</sup>  
Winton Woods Park  
Cincinnati OH 45231

\* \* \*

**Dayton Walk**  
**NEW LOCATION**  
Sunday, September 24<sup>th</sup>  
Day Air Ballpark  
Dayton OH 45402



#### Highlights:

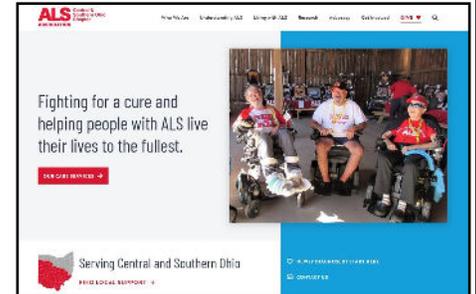
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### New Websites for The Chapter and Walk To Defeat ALS!

We're THRILLED to announce that we have launched a brand new Chapter website! Find us at **ALSohio.org** (without the prefix "www").

You'll find fresh, easy-to-find content that's prioritized for people currently living with ALS and their families. The well-organized menu of topics includes:

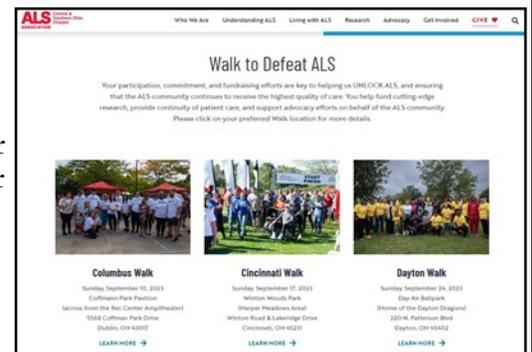
- Actions for those newly diagnosed with ALS
- Facts about ALS, genetic testing, and a glossary of ALS terms
- Local research projects and clinical trials
- Global research funded and strategic research initiatives
- Advocacy accomplishments and public policy priorities
- Information for military veterans
- Resources for caregivers
- Videos and webinars
- Donor impact details and audited financial statements
- Options to subscribe to Chapter newsletters or register to volunteer
- And much more!



We've also launched a new website platform for the Walk to Defeat ALS! You can find it at **ALSohio.org/2023WalkToDefeatALS**. Scroll down, find your city, and register now!

This new site is much easier to use, and will greatly enhance the fundraising experience for team captains, walkers and donors. Your username and password from last year will work, but you will need to re-enter your demographic information and answer a few questions.

We'd love to hear what you think about both websites, and we're here to help if you have questions. Reach out to us at [ALSohio@ALSohio.org](mailto:ALSohio@ALSohio.org) or call us at (866) 273-2572, ext. 101 (for Amy Hall) or ext. 109 (for Melissa Dardinger).



### **2023 Chapter Quality of Life Reimbursement Grant – Please Apply Early!**

The Chapter **2023 Quality of Life Reimbursement Grant** is Open! You can find out if you qualify for the Grant and download the necessary Grant Packet on our local care services page

[2023 Chapter Quality of Life Reimbursement Grant](#)

The Chapter can reimburse up to \$1,200 in eligible expenses to individuals who qualify. Receipts that meet these guidelines can be dated on or after January 5, 2023.

Please obtain your **2023 Chapter Quality of Life Reimbursement Grant** packet early. Funds are limited and grants are approved on a first come, first served basis. 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](mailto:chubbell@alsohio.org).

### **Seeking Businesses for Pin-Up Sales or Sponsorships**

The Chapter is seeking businesses throughout its territory to partner with us for event sponsorships or May ALS Awareness Month pin-up sales. Both the Strike Out ALS and Walk to Defeat ALS sponsorship levels start as low as \$500 - \$750. Pin-up programs offer customers the opportunity to make donations at point-of-purchase at zero cost to the business.

If you know someone who works for – or owns - a business that might want to participate, **please ask them if they would be willing to talk with us about it and we'll take it from there.** Contact Amy Hall, Event Fundraising & Engagement Manager, at (866) 273-2572 x101 or at [ahall@ALSohio.org](mailto:ahall@ALSohio.org). Local businesses are essential partners in our mission to bring free services to people living with ALS and their loved ones.

### **Chapter Link Survey Update**

Thank you to everyone who has taken our survey about the Chapter Link newsletter!

In the next couple of months, we'll be tabulating and analyzing the results. We will use your feedback to make improvements to our newsletter and other communications to give you the information you want, how you want it, and when you want it. We hope to share insights and plans with you sometime after the first of the year.

# UPDATES

## **ALS Association Submits Public Comments in FDA Review of Tofersen**

*Originally posted by ALS.org; edited for space*

On March 8, 2023, The ALS Association submitted comments to the FDA’s Central and Peripheral Nervous System Advisory Committee, urging it to recommend approval of tofersen for people with ALS linked to a *SOD1* gene mutation. The committee will meet virtually on March 22 to review data associated with Biogen’s new drug application.

Biogen is seeking approval of [tofersen](#), an antisense oligonucleotide (ASO) drug, through the FDA's Accelerated Approval Program. According to the FDA, this program was instituted “to allow for earlier approval of drugs that treat serious conditions, and fill an unmet medical need based on a surrogate endpoint.”

Tofersen is designed to block neurons from turning the flawed instructions found in mutated *SOD1* genes into toxic proteins implicated in ALS development. Mutations in the *SOD1* gene appear in about 12-20% of people with familial ALS, and 1-2% of people with ALS who have no family history. The most common *SOD1* gene mutations in North America are associated with younger age of onset and shorter survival.

“SOD1-linked ALS is a particularly rare and aggressive form of an already rare and devastating disease,” said Dr. Neil Thakur, Chief Mission officer of The ALS Association. “Knowing the urgent need for new ALS treatments and based on the data available at this stage, we believe tofersen meets all the conditions required for accelerated approval: treating a serious condition, providing a meaningful advantage over existing therapies and demonstrating an effect on a surrogate marker that is reasonably likely to predict clinical benefit.”

While the phase 3 VALOR trial did not meet its predetermined primary endpoint – a change in the ALS functional rating scale (ALSF<sub>RS</sub>-R) after 28 weeks – tofersen reduced SOD1 protein levels in cerebrospinal fluid by 35% as early as eight weeks after participants began receiving the therapy and further reduced neurofilament light (NfL) levels in blood by 50% within 12-16 weeks, indicating a substantial reduction in the rate of neurodegeneration. High levels of NfL reflect neuron damage, and research has demonstrated a strong link between NfL levels and the risk of ALS development and progression.

The VALOR results suggest that the 28 weeks allotted for the initial blinded phase of the trial were not long enough to demonstrate clinical benefit but were long enough to show biological effects of reducing SOD1 and NfL levels. These reductions translated into a clinical benefit by 52 weeks during the open label extension. Participants who began receiving tofersen during the initial phase 3 trial had a 3.5-point slower decline (on average) in clinical function as measured by ALSF<sub>RS</sub>-R than those who were initially on placebo and began taking tofersen 6 months later. Tofersen also significantly reduced decline in respiratory function, muscle strength and quality of life.

To read the full article, learn how to submit your comments, and to register for a webinar with the lead investigator of the tofersen clinical trials, visit <https://alsohio.org/who-we-are/news-stories>.

# UPDATES

## ALS Research and ALSA Funded Projects at OSU

### Virtual Presentation

Monday, May 1  
6:30 to 8:30 PM

Please join us in welcoming Dr. Steve Kolb and Cheyenne Grove, Clinical Research Coordinator, as they present **ALS Research and ALSA Funded Projects at OSU**. This online event is available to anyone in our chapter, and is hosted by the Columbus Regional Education & Exchange Group.



Dr. Kolb is Professor in the Departments of Neurology and Biological Chemistry & Pharmacology at the Ohio State University Wexner Medical Center, and Director of the OSUWC ALS/MND Multidisciplinary Clinic. He also serves as the OSU Neurology NeuroNEXT Principle Investigator.

Dr. Kolb's research laboratory is focused upon the molecular and cellular mechanisms of motor neuron diseases with the goal of developing effective therapies. His laboratory team has recently developed the first mouse model of a genetic form of ALS associated with mutations in the KIF5A gene and is working to understand how and why this results in ALS.

To join this presentation virtually, please click on the following link or email [chubbell@alsohio.org](mailto:chubbell@alsohio.org) to have a link emailed to you.

<https://v.ringcentral.com/join/575440587>

Meeting ID: 575440587

Or dial:

+1 (650) 4191505 United States (San Mateo, CA)

Access Code / Meeting ID: 575440587

### Student Scholarships Available

The Alice Francis ALS Scholarship Fund is a scholarship for students in the United States whose family is being affected or has been affected within the previous six months by ALS. Eligible applicants: must have a parent, grand parent or guardian who is or was affected by ALS who legally resides or resided in The United States; and, have an annual household income of less than \$50,000. Student age candidate must be enrolled at a school full-time. Adult candidate must already be enrolled at college or trade school. Candidate must not currently be awarded any sports related scholarships.

Candidates should email share their story to [imagine@afals.org](mailto:imagine@afals.org)

# COMMUNITY OUTREACH & CHAPTER EVENTS



## Your Chance to Win \$5K – For You & the Chapter

Cincinnati's Flying Pig Marathon is scheduled for May 7, and that means the Piggest Raffle Ever is right around the corner!

**ADOPT YOUR PIG NOW** for just \$5, at <https://www.piggestraffleever.com>. Each raffle entry is a chance for you to win prizes up to \$5,000 cash! If the winner purchased on behalf of the Chapter, we will also receive up to \$5,000 cash!

**How's it Work? Easy!** Purchase a raffle entry Pig for \$5 each on behalf of The ALS Association Central & Southern Ohio Chapter from the drop-down menu. For each Pig purchased, you have a chance to win on Flying Pig Marathon Weekend and the Chapter will receive 100% of your donation!



**Raffle Details:** Entry deadline is **Saturday, May 6**; drawing held on **Sunday, May 7**. You do not need to be present to win but everyone is welcome to join in race weekend!

DRY CAMPING AVAILABLE - RAFFLES - FOOD - DOOR PRIZES

# WANTED

## RACING MOWERS & KARTS

MOW DOWN

2 BROTHERS RACEWAY - 9068 LIMRICK RD - CHILLICOTHE OH

**SEPTEMBER 22ND GATES OPEN AT 10 AM**  
PIT PARTY TO FOLLOW  
SPONSORED BY: SCOOTERS BAR & GRILL

**SEPTEMBER 23RD - RACE**  
GATES OPEN AT 10 AM

SPONSORED BY  
BIG DOG PIZZA - SCOOTERS BAR & GRILL - THE PROFESSOR OF HORROR - BUCKEYE SLACKER CASSIS - MICHIGAN MOWER RACING ASSOCIATION - OMRA - ELITE MOWER RACING - CML SERVICES - MANGIE FILMS - ALTERED MINDS PRODUCTIONS

**Community Partner**  
An Event To Benefit  
The ALS Association  
Central & Southern Ohio Chapter

# WHIFFLE GOLF TOURNAMENT

Fundraiser for ALS Association – Central & Southern Ohio  
In memory of Nancy Endejann

**Sunday, April 16, 9am-3pm**

Hosted by El Coyote Restaurant

7404 State Road, Anderson Twp.

Food and beverages available at restaurant

Suggested Donation: \$25/adult, \$20/kids => 10  
Limited to 9-irons and wedges; whiffle golf balls provided

Call **513-377-8350** for tee times



# COMMUNITY OUTREACH & CHAPTER EVENTS



## TWO (2) FREE TICKETS!

People with ALS in our Chapter territory can reserve two free tickets to one (1) Strike Out ALS game (Reds, Clippers, or Dragons).

1. Contact Tina Pinardi to reserve your tickets at [tpinardi@alsohio.org](mailto:tpinardi@alsohio.org) or 866-273-2572, ext. 100.
2. Pick up your tickets at Will Call - ID required.
3. Invite your friends and family to purchase additional tickets and join you for a night of fun!



## DAYTON DRAGONS vs. Lake County Captains

Friday, June 23, 2023

Game begins at 7:05 PM

Day Air Ballpark, 220 N Patterson Blvd, Dayton, OH 45402

Purchase tickets at  
<https://fevogm.com/ALSassociation8>

### Each \$55 Ticket Includes:

- Private seating in the Dragons Lair
- Buffet with food and drinks
- Dragons hat and Dragons t-shirt
- Pre-game ceremony with ALS honoree throwing out the first pitch
- Strike Out ALS t-shirts and other merchandise available for purchase
- A portion of your ticket price goes to the Chapter to support people living with ALS



## COLUMBUS CLIPPERS vs. Toledo Mud Hens

Friday, June 30, 2023

Game begins at 7:05 PM

Huntington Park, 330 Huntington Park Ln, Columbus, OH 43215

Purchase tickets at  
<https://fevo.me/strikeoutals2023>

### Each \$55 Ticket Includes:

- Private seating on the Pepsi Party Deck AND the adjacent Pedialite Porch!
- Buffet with food and drinks
- **NEW! Cash bar on the Party Deck** (domestic & craft beers, seltzers, well liquor)
- Pre-game ceremony with ALS honoree throwing out the first pitch
- Strike Out ALS t-shirts and other merchandise available for purchase
- A portion of your ticket price goes to the Chapter to support people living with ALS

# COMMUNITY OUTREACH & CHAPTER EVENTS

## Strike Out ALS



JOIN US FOR LOU GEHRIG DAY!



**ALS**  
ASSOCIATION

Central & Southern  
Ohio Chapter

**CINCINNATI REDS vs.  
Milwaukee Brewers**

Friday, June 2, 2023  
Game begins at 5:10 PM

Great American Ball Park  
100 Joe Nuxhall Way, Cincinnati, OH 45202

### DON'T MISS THESE EXCITING EVENTS:

- ALS honoree throwing first pitch!
- Opening ceremony for ALS awareness! (time to be announced soon)
- All-inclusive food and drink buffet, with 2 beers per guest!
- Plus a post-game concert by the Zac Brown Band!

### TICKETS ARE LIMITED; RESERVE YOURS NOW!

Due to expected high demand, we have reserved two locations for our Chapter community. To ensure as many people as possible have the opportunity to enjoy this experience, we are staggering ticket sale dates and limiting tickets per person for this event. Please see details below.

- 2 FREE tickets are available for each of our friends living with ALS (PALS) who are registered with the Chapter. Please contact Tina Pinardi at [tpinardi@ALSOhio.org](mailto:tpinardi@ALSOhio.org) or 866.273.2572 x100 to reserve your two free tickets.
- Additional tickets are \$100 each, limit 4 per person (in addition to the 2 free tickets for PALS). Contact Tina Pinardi (info above) to purchase.
- February 1 to 28: Tickets are available ONLY to Cincinnati-area PALS.
- March 1 to 31: Tickets will be available to remaining Chapter PALS.
- April 1 to June 2: Tickets will be open to the general public as they last.
- Pick up your tickets at Will Call on game day (must present a valid ID).
- \$10 of your ticket price goes back to the Chapter to support people living with ALS. A portion of the Reds ticket price also benefits the Hop On a Cure Foundation, founded by Zac Brown Band member John Driskell Hopkins.

**PLUS**  
post-game concert by  
**ZAC BROWN BAND!**

### Choose from 2 prime seating locations:

#### Tire Discounters Party Deck

This is our annual space along right field; semi-covered decks, private restrooms, plenty of accessible space, high-top tables and chairs, and cushioned ballpark seating.

#### Trihealth Center-Field Pavilion

NEW! This indoor area behind center field is climate-controlled with plenty of accessible space and lounge seating.





**Zac Brown Band**

POST-GAME BENEFIT CONCERT

**JUNE 2, 2023**

GREAT AMERICAN BALL PARK

ALS

The concert, which will be the band's only Cincinnati area appearance in 2023, will follow the Reds vs. Brewers game and feature a full Zac Brown Band set. For more concert details, visit <https://www.mlb.com/reds/tickets/concerts/post-game/zac-brown>.

# REMEMBERING

Cincinnati Area		Columbus Area		Dayton Area		Lima Area
Jean Young	3-11-23	Ray Swinehart	3-9-23	Steve Studebaker	3-15-23	
Kevin Johnson	3-9-23	John Sarver	2-28-23	Jayantibha Patel	3-14-23	
		Brett Tawney	2-23-23	Paul Miracle	2-27-23	
				Anthony Stauffer	2-22-23	

# FREE FOR PALS

**Men's Pair of "Kiziks" Shoes**—size 8.5 NEW, never worn. Color Gray, Easy slip on and off.  
**Contact Susan by text at 614-975-3385**

**Men's snap and zip clothing - Contact: Jenniffer Acton at 513-404-4123 or [jacton3695@gmail.com](mailto:jacton3695@gmail.com)**  
 Please leave a message.

**Hospital Bed**—used in Good Condition, a **6-foot, Tri-fold Prairie View Industries Metal Ramp.**  
 If interested, please **Contact: Mary Ann at 419-234-3837** Located in Putnam County

**-Alternating air pressure mattresses (2), -Boogie boards, -Foam wedges (one small; one large), -Syringes (20+), -Cotton tipped applicators, -Swab sticks, -Drain sponges (split), -Jevity 1.2 (3.5 cases)**  
**-Gait belt, -Healthy Shot protein shots, peach, (1 case), -Hand braces, -Shoulder brace, -Neck braces (2) (soft), -feeding tube holder and - hair dryer holder.** Items will need to be picked up. Located in Findlay. If interested, please **contact: Lee at (419) 348-5908**

**Respiratory Supplies, Oral Suction Supplies, Oral Swabs, Suction Catheters, Suction Cannister Bottles—**  
**Contact: Mark Withey at Advanced Home Medical in Columbus—[mwithey@advhmed.com](mailto:mwithey@advhmed.com)**

**Convaid Rodeo Tilt Stroller** is a lightweight stroller that folds and tilts for comfort and support! Designed with caretakers in mind, this special needs tilt-in-space stroller fits children approximately 4 years old to small adults. <https://www.especialneeds.com/convaid-rodeo-tilt-stroller.html> If interested. Please **Text: 513.936.0986**  
 We have just begun collecting our thoughts on items that we have and won't need anymore. These items will be useful for others, but thought to get the message out in this month's newsletter. **Please text or email for a list of FREE items to: Peter, Cincinnati, [communications.confidential@gmail.com](mailto:communications.confidential@gmail.com). Text: 513.936.0986**

# FOR SALE

**2017 Red Chrysler Pacifica Limited Edition (7/23)** - Excellent condition w/39,025 miles, BraunAbility XT conversion. Purchased from MobilityWorks for \$62,723 in 12/2022. Only 505 miles on vehicle. Asking \$48,500. **Please contact Kent at 614-203-9509 or [kentsmith65@outlook.com](mailto:kentsmith65@outlook.com)**

**Nitro Rollator Walker (5/23)** Asking \$150.00 - email Joan - [jmmiller30@aol.com](mailto:jmmiller30@aol.com)

**Hill ROM Care Assist ES Hospital Bed (5/23)** with Prius Rhythm multi- alternating, low air loss, pressure relief system with lateral rotation-\$2,500 **Permobil F3-** midnight patriot w/ seat elevator, attendant controller, adjustable phone & iPad holders-\$2,000 **Adjustable Hospital Table-\$50** **Combination Commode/Shower Chair-\$200** **Wheelchair Ramp & Platform,** 2- 3 ft sections, 2- 8 ft sections, 1- 5x5 platform, and rails. Buyer will have to disassemble and move. \$1,800 If interested, please **Contact: Jenniffer Acton at 513-404-4123** or [jacton3695@gmail.com](mailto:jacton3695@gmail.com) Please leave message.

**2016 Toyota Sienna XLE Limited (5/23)** (VIN 5TDYK3DC9GS707477) in Blizzard Pearl White with a Genesis side entry conversion, 63,000 miles. Asking \$36,000 Or Best Offer. Mobility conversion includes; Side entry includes a remote controlled extension ramp and squat feature, Removable Driver and Passenger Seats, Multiple Floor Anchor points, a Medical Chair Docking Station in the Front Passenger Seat location. Engine 3.5L V6 Transmission 6-Speed Automatic Safety; Enhanced Vehicle Stability Control, Traction Control, Anti-Lock Brake System, Electronic Brake-Force Distribution, Brake Assist & Smart Stop Technology Driver & Front Passenger Active Headrests 8 Airbags  
Interior: Push Button Start 7" Touch-Screen,AM/FM/CD/USB/AUX, Bluetooth, SXM , HD Radio, Backup Camera, Sunroof, Easily clean flooring. Exterior; Projector-Beam Headlights with Auto On/Off, Dual Power Sliding SideDoors & Power Liftgate, Integrated Wide-Angle Fog Lights, Blind Spot Monitor/Rr Cross Traffic Alert, Power Tilt / Slide Moonroof, Roof Mounted Luggage Rack. **If interested, please contact at 513-575-0505 or via email [carolen@fiotics.com](mailto:carolen@fiotics.com)**  
**Sara Steady Manual Sit-to-Stand Lift (5/23)** in excellent condition. Asking \$500 Please **Contact: 513-575-0505**

**MOLIFT Duo 2 Post Rails System & Air Bundle Kit (5/23)** used for less than 2 weeks, Asking \$3,200 located in Putnam County. If interested, please **Contact: Mary Ann at 419-234-3837**

**Quantum Q6 Edge powered wheelchair (6/23)** 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](mailto:gh200001@hotmail.com)**

**Invacare Hydraulic Lift Model 9805P (4/23)** 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](mailto:tara15935@gmail.com)**

**Indoor Wheelchair Lift (1/23) Model VPL-3210B.** Capacity 750 lbs. Platform size: 36" x 54". Platform Configuration: Enter/Exit same side. Platform Controls: Rocker Control w/ Emergency Stop. Top Landing: 36" Gate Electrical mechanical Interlock + Rocker Control w/ Call/Send Mounted in Frame. Bottom Landing: Call/Send - Surface Mount w/ Rocker Control. Bottom Landing Door: Door Baffle for Door by Buyer. No Pit - 3" stationary ramp. Travels up to 123". Used to travel from main level to basement. **Contact Heather @ 630-440-8547 for further details and pictures.**

**2008 Dodge Grand Caravan SXT (12/22)**– AMSVANS.com Handicap conversion van (lowered floor, center seats removed, side powered wheelchair ramp; had an EZ Lock BL-6290 wheelchair docking base, removed but available; we got four ratchet ties installed), low 49,000 miles, gently used last 8 years, maintained well, garage parked. Asking \$14,000 OBO.

**For questions, pictures email: Peter, Cincinnati, [communications.confidential@gmail.com](mailto:communications.confidential@gmail.com). Text: 513 936 0986**

**F3 Permobil Power Wheelchair (9/22)** \$3,500 or OBO. Indoor **Electric Hoyer Lift** with 2 half slings, 1 full body sling, 3 batteries and charger \$150 OBO **Please contact Jennifer VanHorne at (614) 849-8613 or email : [javh1965@gmail.com](mailto:javh1965@gmail.com)**

# Caregiver & Survivor Groups

<p><b>CINCINNATI CAREGIVER GROUP</b> (current caregivers only)</p>	<p>No Group This Month</p>		<p>Yvonne Dressman, LSW</p>	<p>The Good Shepherd Lutheran Church 7701 Kenwood Rd Cincinnati, OH 45236</p>
<p><b>CENTRAL OHIO CAREGIVER GROUP</b> (current caregivers only)</p>	<p>Monday April 17, 2023 1:00—2:30 pm</p>	<p>Open Discussion</p>	<p>Carleen Hubbell, BS, MA</p>	<p>Virtual Only <a href="http://v.ringcentral.com/join/575440587">http://v.ringcentral.com/join/575440587</a> Meeting ID: 575440587 Or dial: +1 (650) 4191505 United States (San Mateo CA) Access Code/Meeting ID: 575440587</p>
<p><b>CENTRAL OHIO SURVIVOR GROUP</b></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>Carleen Hubbell</p>	<p>Hunan Lion 2038 Crown Plaza Drive (off Bethel Road) Columbus, OH 43235</p>
<p><b>CINCINNATI AREA SURVIVOR GROUP</b></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><b>GREATER DAYTON IN-PERSON SURVIVORS GROUP</b>  Meets Tri-annually 4th Wednesday</p>	<p>Wednesday June 28, 2023 Sept 27, 2023  6:00 pm—8:00 pm</p>	<p>Our Survivors Group is a social dinner to enjoy the company of friends who have experienced loss to ALS- to stay connected with peers &amp; our Chapter.  <i>Dinner on Your Own</i></p>	<p>Facilitators  Mary Helme Claire Robbins Whitney Taverna Bob Westendorf</p>	<p><b>LOCATION</b> T B D Group will meet at different restaurants each month  **Must RSVP to Whitney** Email: <a href="mailto:wtaverna@alsohio.org">wtaverna@alsohio.org</a> Text: 614.259.2066 Phone: 937.525.0930</p>

# The ALS Association Central & Southern Ohio Chapter Chapter-Wide Education and Exchange Groups

DATE	TOPIC	LOG-IN/CALL-IN INFORMATION
<p style="text-align: center;"><b>Monday</b> <b>April 10, 2023</b> <b>6:00 pm—8:00 pm</b> <b>Facilitator:</b> <b>Yvonne Dressman</b></p>	<p style="text-align: center;"><b>CINCINNATI REGIONAL AREA</b> <b>ALS Communication 101:</b> <b>low and high tech options</b> <b>Dr. Amanda Simmons</b></p>	<p style="text-align: center;"><b>In-Person Support Group</b> <b>The Good Shepherd Lutheran Church</b> <b>7701 Kenwood Rd</b> <b>Cincinnati, OH 45236</b></p>
<p style="text-align: center;"><b>Monday</b> <b>April 3, 2023</b> <b>6:30 pm –8:30 pm</b> <b>Facilitator:</b> <b>Carleen Hubbell</b></p>	<p style="text-align: center;"><b>COLUMBUS REGIONAL AREA</b> <b>ALS Programs and Services</b> <b>Followed by</b> <b>Open Discussion</b></p>	<p style="text-align: center;"><b>Virtual Only</b> <a href="http://v.ringcentral.com/join/575440587">http://v.ringcentral.com/join/575440587</a> <b>Meeting ID: 575440587</b> <b>Or dial:</b> <b>+1 (650) 4191505 United States (San Mateo CA)</b> <b>Access Code/Meeting ID: 575440587</b></p>
<p style="text-align: center;"><b>Monday</b> <b>April 3, 2023</b> <b>1:00pm-2:30 pm</b> <b>Facilitator</b> <b>Whitney Taverna LISW-S</b></p> <p style="text-align: center;"><i>1st Monday of each Month</i></p> <hr/> <p style="text-align: center;"><b>Monday</b> <b>April 17, 2023</b> <b>6:30pm—8:30 pm</b> <b>Facilitators:</b> <b>Whitney Taverna</b> <b>Bob Westendorf</b> <b>Julia Prince</b> <i>3rd Monday of each month</i></p>	<p style="text-align: center;"><b>GREATER DAYTON/Mid-NW REGION</b> <b>Virtual Open Discussion—Q&amp;A</b></p> <hr/> <p style="text-align: center;"><b>GREATER DAYTON/MIAMI VALLEY REGION</b> <b>ALS Symptom Management</b> <b>Dr. Jonathan Strayer &amp; Marlene Davis-Pierce</b> <b>Dayton VAMC Spinal Injury Clinic</b></p>	<p style="text-align: center;"><b>Virtual or Call-In Only</b> <a href="https://v.ringcentral.com/join/240430372">https://v.ringcentral.com/join/240430372</a> (Meeting ID:240430372) or by phone: (650) 419-1505 access code/ Meeting ID 240430372</p> <hr/> <p style="text-align: center;"><b>In-Person Location</b> <b>Beavercreek Christian Church</b> <b>3009 Shakertown Road</b> <b>Beavercreek, OH 45434</b> <b>(Please drive to back of church to park.</b> <b>Our room is Multipurpose Room 212</b> <b>and accessible only thru back door.)</b></p>
<p style="text-align: center;"><b>Monday</b> <b>April 24, 2023</b> <b>6: 00 pm—8:00 pm</b></p>	<p style="text-align: center;"><b>CHAPTERWIDE VIRTUAL</b> <b>Alisa Brownlee, ATP, CLIPP, CAPS, WSP</b> <b>Assistive Technology Specialist/Consultant</b> <b>Chapter Care Services</b>  <b>Home Modifications for Safety &amp; Accessibility</b></p>	<p style="text-align: center;"><b>Virtual Only</b> <a href="http://v.ringcentral.com/join/575440587">http://v.ringcentral.com/join/575440587</a> <b>Meeting ID: 575440587</b> <b>Or dial:</b> <b>+1 (650) 4191505 United States (San Mateo CA)</b> <b>Access Code/Meeting ID: 575440587</b></p>

### Updated Information Regarding In-Person Education & Exchange and Caregiver Groups

As case numbers for Covid-19 continue to decrease in Ohio, the Chapter has decided to restart indoor Education & Exchange and Caregiver groups in certain areas, based on requests that we have received from families. The former restrictions that were put in place over the last several months, including mandatory masks and proof of vaccination will be lifted. Due to the risks that Covid infection presents to people with ALS, the Chapter strongly encourages group attendees to be vaccinated and to continue masking at indoor groups. If Covid-19 cases should spike over 50/100,000 cases in Ohio, the Chapter will reinstate the former restrictions until numbers stabilize. A Chapter-wide, virtual group option will continue

# REMINDERS

## Monthly Chapter-Link Newsletter Mailings

The Chapter-Link is mailed to all patients who are registered with the Chapter. When individuals are no longer actively receiving services through the Chapter, 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](http://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 the Chapter in memory of their loved one. This can be done by naming the Chapter in your loved one's obituary: Memorial donations may be made to The ALS Association Central & Southern Ohio Chapter, 1170 Old Henderson Rd., Ste. 221, Columbus OH 43220. The Chapter sends 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 Association Central & Southern Ohio Chapter 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 the Chapter website, <https://alsohio.org/navigating-als/resources-for-military-veterans>.

## ALS Information for Kids and Teens

The Central & Southern Ohio Chapter is 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 The ALS Association Connecticut Chapter. Working from this model, the Central & Southern Ohio Chapter 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 Chapter Care Services (866) 273- 2572. Learn more at <https://alsohio.org/resources-for-children-and-teens>.

## ALS Wristbands and Magnetic Car Ribbons

The ALS wristbands are available for purchase through The ALS Association Central & Southern Ohio Chapter office. The wristbands are red silicone with "Fighting Lou Gehrig's Disease" on the outside and "The ALS Association Central & Southern Ohio Chapter" on the inside. Cost for the wristbands is \$2.00 per wristband plus postage. Magnetic "Fighting Lou Gehrig's Disease" car ribbons are also available from The ALS Association Central & Southern Ohio Chapter office. Individual magnets can be purchased for \$5.00 each. Orders of five or more are available for \$4.00/magnet plus \$4.00 shipping. For more information, call (614) 273-2572 or toll free (866) 273-2572



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Our monthly newsletter includes ads from companies that are actively involved in services to the ALS community. The Chapter is grateful to these "friends" not only for their support of The ALS Association Central & Southern Ohio Chapter, 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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