



The Chapter-Link

May 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 10th
Coffman Park Pavilion
Dublin OH 43017

* * *

Cincinnati Walk
Sunday, September 17th
Winton Woods Park
Cincinnati OH 45231

* * *

Dayton Walk
NEW LOCATION
Sunday, September 24th
Day Air Ballpark
Dayton OH 45402

Jane Calmes Scholarship Available

For the fifth year, The ALS Association is now accepting applications for The Jane Calmes ALS Scholarship Fund, which was established in 2019 to support post-high school education for students whose lives have been impacted by ALS. Scholarship recipients receive up to \$5,000 per year to help cover the cost of two- or four-year college degrees or vocational education.

Applications for this year’s scholarship awards, which will be distributed for the fall 2023 and spring 2024 semesters, are being accepted now through May 18, 2023.

Since its inception, the fund has awarded more than \$1,500,000 in over 300 scholarships to students nationwide who are pursuing an accredited college degree or vocational certificate.

To apply for The Jane Calmes ALS Scholarship Fund awards, visit <https://learnmore.scholarsapply.org/calmesscholarshipfund/>.

Camp HLC (Hope Loves Company) June 18-23

Camp HLC Indiana is happening June 18-23 at Flat Rock River YMCA Camp, 6981 W Co Road 650 N, St Paul, IN 47272. This is a FREE week-long retreat for children, teens, and young adults affected by ALS. Transportation assistance to get to and from camp is available from Camp HLC. Register at hopelovescompany.org.

Visit our New Website at ALS.org

We’re proud to share that the Chapter has a New & Improved website! Find us at ALSohio.org (without the prefix “www”).

There’s fresh, easy-to-find content that’s prioritized for people currently living with ALS and their families. Find the latest research news, local clinical trials, and Chapter events. Look for resources to help the children in your life understand your diagnosis. Register for upcoming events, and learn more about your local ALS community.

Highlights:

General News	2
Updates	3
Chapter Events	5
Remembering	8
For Sale	9
Support Groups	10-11
Reminders	12

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.

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. 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 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. To join this presentation virtually, please click on the following link or email 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

FDA Committee Unanimously Recommends Accelerated Approval of Tofersen

Originally posted by ALS.org

The FDA Peripheral and Central Nervous System Drugs Advisory Committee voted 9-0 that a reduction in plasma neurofilament light (NfL) concentration is “reasonably likely” to predict clinical benefit of tofersen for treatment of patients with SOD1-ALS. On a second question, the committee voted 5-3 (with one abstention) that the clinical data surrounding tofersen does not provide “convincing evidence” of effectiveness of tofersen in the treatment of patients with SOD1-ALS. These votes support FDA approving tofersen under the [accelerated approval pathway](#).

In response, we issued the following statement:

“We thank the FDA Advisory Committee for their clear and compelling recommendation that tofersen be approved under the accelerated approval pathway. We urge the FDA to swiftly approve this urgently needed new treatment. Americans living with this rare and aggressive genetic form of ALS cannot wait.”

Several people living with ALS and leading ALS advocates spoke during a public forum in support of the first-of-its-kind drug treatment targeting a genetic cause of ALS.

“Knowing there is a treatment for this form of ALS, and better yet, potentially a way to prevent the disease from ever manifesting itself, would not only save me but also give my children the freedom to live their lives without this weight on their shoulders,” said Larry Falivena, who was diagnosed with SOD1-linked ALS. “Tofersen is the opportunity to break the cycle of genetic ALS for families who have been devastated by the disease for generations.”

Calaneet Balas, President and CEO of The ALS Association, also testified at the hearing, and stated that the ALS Association only makes recommendations on drug approvals after conducting a thorough independent peer-review process. Based on this analysis, the Association believes tofersen meets all the conditions required for accelerated approval.

“We respectfully request you make a favorable recommendation to the FDA, supporting accelerated approval of tofersen,” Balas told the advisory committee. “People with SOD1-linked ALS and their health care providers should have full access to this drug as soon as possible.”

An FDA decision is expected by April 25.

UPDATES

ALS Awareness Month Events

May is ALS Awareness Month, and this year there are several ways to get involved. Celebrate with us and visit one of the generous companies below that are helping us celebrate by providing donations to our Chapter.

Event	Date	Location	Details
Online Auction	5/1 - 5/7	Online	A selection of items donated to the Chapter will be available for bid, along with larger-scale experiences.
Sonder Brewing Night	5/2 and All Month	Cincinnati	Event runs from 5-8pm. 10% of sales from draft pours of a specialty beer all month long will be donated to the Chapter, and 20% of sales of that beer will be donated to the Chapter during the event on 5/2.
Old Scratch Pizza	5/9	Dayton	Event runs from 4-8pm. Old Scratch Pizza will donate \$500 to the Chapter, plus free pizza in the private room for ALS attendees.
Seventh Son Brewing	5/11	Columbus	\$1 from every beer and Kittybrew Seltzer sold all day will be donated to the Chapter.
Star Lanes Spirit Day	5/16	Columbus	Event runs from 11am-8pm. 10% of all purchases from bowling, shoes, arcade, food, and non-alcoholic beverages will be donated to the Chapter.
Moeller Brew Barn	5/23	Dayton	Event runs from 5-9pm. 20% of all food and beverage is donated to the Chapter.
Rhinegeist Night	5/24 and All Month	Cincinnati	Chapter staff will be on site from 5-8pm on 5/24. Vote for our Chapter with your token from every drink purchased, every Wednesday through May. Charity with most "votes" receives \$700 from Rhinegeist.
Aladdin's Eatery	All Month	Columbus	All 5 Columbus-area Aladdin's locations will be selling pin-ups for \$1 throughout the month of May.
James Free Jewelers	All Month	Dayton	Free watch battery replacement (up to three timepieces) with charitable donation. 100% of donations are given to the Chapter.

Register Today for the 2023 Walk to Defeat ALS!

Registration is now open for the 2023 Walk to Defeat ALS. If you haven't registered already, don't wait – register today! Invitations are going out to all registered team captains for the Walk Kickoff luncheons in June, where you'll get tips and ideas for a successful Walk season, get help with registration, and enjoy great food and friends.



Visit our new Walk website 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.

COMMUNITY OUTREACH & CHAPTER EVENTS



2116 Tremont Center, Upper Arlington • 614-488-8777

Here's a sweet way to support Team OhioHealth on their Walk to Defeat ALS!

For every dozen cinnamon sticks you buy May 1-13, The Goodie Shop will donate \$2.50 to their fundraiser!



Cinnamon sticks are layers of sweet roll dough and korintje cinnamon sugar coated in a brown sugar buttery glaze. Every bite is like the center of a cinnamon roll! Cinnamon sticks freeze well, so stock up & support a great cause!

Make copies for friends and family prior to shopping!
This flyer will be surrendered at time of purchase. Valid May 1-13, 2023.



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!

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

EAT PIZZA RAISE DOUGH



MONDAY, MAY 23

4:00 - 9:00



All supporters, family, and friends are invited to eat pizza and raise funds! Mention this flyer when ordering and up to 20% of all food purchases will be donated to the ALS Association Central & Southern Ohio Chapter. Co-hosted by Jan Bowden in honor of her late husband, Dick Bowden. All proceeds donated will go toward Jan's Walk to Defeat ALS Team.

Order Online: deweyspizza.com [mention "GBN" in Order Notes]

DEWEY'S PIZZA, AUSTIN LANDING
3600 RIGBY RD | 937.859.7777



Valid only on 5.23.22 at Dewey's Pizza Austin Landing.
Not valid with DoorDash delivery.

COMMUNITY OUTREACH & CHAPTER EVENTS



TWO (2) FREE TICKETS FOR PEOPLE WITH ALS!

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

1. **Contact Tina Pinardi** to reserve your 2 free tickets at 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 (at the links below)** 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 Pedalite 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 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

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
Jason Lee O’Nan 4-6-23	Gerald Picker 4-12-23	Leon Lacy 3-30-23	
Max Kiep 4-2-23	Barbara Harris 4-10-23	Robert Sankey 3-22-23	
Scott Hargue 3-14-23	Dianna Wyche 4-1-23		
	Lynda Cavalaris 3-30-23		
	William Maguire 3-26-23		
	Robert Pauley 3-16-23		

FREE FOR PALS

Sliding Bath Chair - Cough Assist Machine - 2 Tube Feed Poles - 8 boxes of Kate Farms Peg tube food and gravity bags- Bi-Pap Machine and lots of new tubing and masks. For information on items listed, please **Contact: Suzie at 614-975-3385 or email suzepicker@gmail.com**

Women’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
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 Witchey at Advanced Home Medical in Columbus—mwitchey@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. Text: 513.936.0986**

FOR SALE

Wheelchair Lift- (8/23) Indoor or garage. Model VPL-3153B, Capacity 750 lb. Platform size 36" x 60". Platform Configuration: Enter/Exit opposite. Top Landing: Gate w/ call/send mounted in frame. Travels up to 3.5 feet. Used in the garage to travel to the main level. Asking \$3500. Excellent condition. **Contact Suzie at 614-975-3385 or email suzepicker@gmail.com**

2015 Dodge Grand Caravan (8/23) (maroon) with 93K miles - 40,000 miles on new tires; brakes from 2019. Asking \$20K. **Contact Michelle phone/text @ 937-689-0235 or email at guitighermm@gmail.com.**

2019 White Dodge Grand Caravan SXT (8/23) (VIN: 2C4RDGCG5KR772208). Excellent Condition with 56200 miles. Flex-Fuel capable. BraunAbility Conversion, with center passenger side power folding EZ ramp, Rubber, easy-cleanable flooring. Purchased from MobilityWorks on 09/22. Asking \$46,500, OBO. **Please contact Charles at 937-335-1411 or at cskira@woh.rr.com.**

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**

Nitro Rollator Walker (5/23) Asking \$150.00 - email Joan - 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** 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, Sun-roof, 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 Moon-roof, Roof Mounted Luggage Rack. **If interested, please contact at 513-575-0505 or via email carolen@fioptics.com**
Sara Stedy 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**

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.**

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**

Caregiver & Survivor Groups

<p>CINCINNATI CAREGIVER GROUP (current caregivers only)</p>	<p>Tuesday May 23, 2023 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 (current caregivers only)</p>	<p>Monday May 15, 2023 1:00—2:30 pm</p>	<p>Open Discussion</p>	<p>Carleen Hubbell, BS, MA</p>	<p>Virtual Only http://v.ringcentral.com/join/575440587 Meeting ID: 575440587 Or dial: +1 (650) 4191505 United States (San Mateo CA) Access Code/Meeting ID: 575440587</p>
<p>CENTRAL OHIO SURVIVOR GROUP</p>	<p>Thursday May 18, 2023 11:45 am—1:00 pm</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>Hunan Lion 2038 Crown Plaza Drive (off Bethel Road) Columbus, OH 43235</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 Meets Tri-annually 4th Wednesday Next Meeting 9/27/23</p>	<p>Wednesday June 28, 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 & our Chapter. <i>Dinner on Your Own</i></p>	<p>Facilitators Mary Helme Claire Robbins Whitney Taverna Bob Westendorf</p>	<p>LOCATION T B D Group will meet at different restaurants each month **Must RSVP to Whitney** Email: wtaverna@alsohio.org 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
Monday May 8, 2023 6:00 pm—8:00 pm Facilitator: Yvonne Dressman	CINCINNATI REGIONAL AREA Medicare/Medicaid, Advance Directives and Estate Planning Mollie Stegman, Eldermed Attorney at Law	In-Person Support Group The Good Shepherd Lutheran Church 7701 Kenwood Rd Cincinnati, OH 45236
Monday May 1, 2023 6:30 pm –8:30 pm Facilitator: Carleen Hubbell	COLUMBUS REGIONAL AREA ALS Research and ALSA Funded Projects at OSU Dr. Kolb, Professor, Department of Neurology, Biological Chemistry & Pharmacology at OSU Wexner Center (OSUWC)and Director of the OSUWC ALS/MND Multidisciplinary Clinic and serves as the OSU Neurology NeuroNEXT Principle Investigator and Cheyenne Grove, Clinical Research Coordinator	Virtual Only http://v.ringcentral.com/join/575440587 Meeting ID: 575440587 Or dial: +1 (650) 4191505 United States (San Mateo CA) Access Code/Meeting ID: 575440587
Monday May 15, 2023 6:30pm—8:30 pm Facilitators: Whitney Taverna Bob Westendorf Julia Prince 3rd Monday of each month	GREATER DAYTON/MIAMI VALLEY REGION Mobility Options & Considerations for Accessibility Craig Rowitz, PT, MPT, ATP Care Medical Inc. 1st hour Education; 2nd hour Open Discussion, Q & A with split groups for Caregivers & pALS	In-Person Location Beavercreek Christian Church 3009 Shakertown Road Beavercreek, OH 45434 (Please drive to back of church to park. Our room is Multipurpose Room 212 and accessible only thru back door.)
Monday July 24, 2023 6: 00 pm–8:00 pm	CHAPTERWIDE VIRTUAL Frontal-Temporal Lobe Dementia & ALS Dr. Russell Sawyer, UC Neurologist Specialist in Behavioral Neurology/FTLD	Virtual Only http://v.ringcentral.com/join/575440587 Meeting ID: 575440587 Or dial: +1 (650) 4191505 United States (San Mateo CA) Access Code/Meeting ID: 575440587

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 to be made available to anyone not wishing to attend an in-person, indoor meeting.

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

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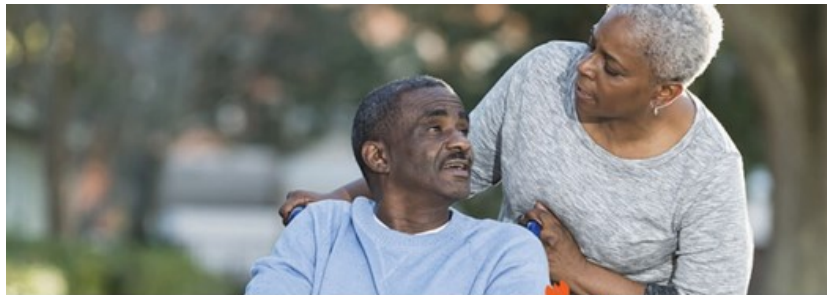
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Our monthly newsletter includes ads from companies that are actively involved in services to the ALS community. The Chapter is grateful to these "friends" not only for their support of The ALS Association Central & Southern Ohio Chapter, but also for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