



# The Chapter-Link

## July 2022

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### 2022 EVENTS

**Dayton Food Truck  
Rally for ALS  
Saturday  
July 23, 2022  
from  
3:00-9:00 pm**

\* \* \* \*

**5th Annual  
Mow Down  
September 24, 2022**

*See Details*

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### Join Us As We Walk To Defeat ALS!

The Walk to Defeat ALS will be here before you know it! It's our first Walk in-person since 2019, and we're eager to host an event that you won't want to miss. We'll have food trucks, popular characters, mascots, merchandise, and so much more!

You may know that the money raised through these Walks accounts for 70-75% of Chapter revenue each year. But, more importantly, it's a celebration – a time to see old friends and make new ones, remember those who have passed, honor those living the fight, and act upon your passion to fight ALS – all in one big party!

Here are some tips and opportunities to get you started.

#### How to Register

Visit [bit.ly/2022WalkToDefeatALS](http://bit.ly/2022WalkToDefeatALS) or call Amy Hall at the Chapter Office to register by phone, (866) 273-2572 x100.

#### Earn a Free T-Shirt

Donate or raise \$90 or more and receive a free 2022 Unlock ALS t-shirt! This benefit is awarded to individuals, not teams or donors, so make sure the donations to your personal fundraising record add up!



#### Family and Pet Friendly – Walking Not Required

You don't have to walk the route to join us for the celebration. Feel free to bring a weighted pop-up tent, chairs, food, and non-alcoholic beverages. Pets on leashes are welcome.

#### Fundraising Help Every Step of the Way

For a copy of the complete Walker Handbook with tools, tips, FAQs and more, visit [bit.ly/2022WalkToDefeatALS](http://bit.ly/2022WalkToDefeatALS) or contact us; we'll be happy to send you a copy in the mail. Inside you'll find template emails and social media posts to help your fundraising, 9 easy ways to jumpstart your fundraising, ways to share your digital activity, details about the Walk App, and much more.

. . . . *Continued on page 9*

#### Highlights:

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## **Quality of Life Reimbursement Grant**

This year the Chapter can reimburse individuals who qualify for the **Quality of Life Reimbursement Grant** up to \$1,200 in acceptable expenses.

For more information, or to apply for the grant: Please call or email care services coordinator Carleen Hubbell. She can be reached at – 614.273.2572 extension 110, or [chubbell@alsohio.org](mailto:chubbell@alsohio.org). You can also find more information on the Chapter **Quality of Life Reimbursement Grant and the Grant Application** on the Chapter website - [Quality of Life Reimbursement Grant](#)

## **Learning Opportunities**

**ALSA Care Services Webinars** To access archived Care Services webinars, please go to <https://www.als.org/navigating-als/resources/care-services-webinars>. A full list of past webinars are available to view.

**Please subscribe to the ALS Association Central & Southern Ohio Chapter YouTube Channel!** Click or enter <https://www.youtube.com/channel/UCYFRx5hmu3Zy-ks5ZkjFVgw> and click the Subscribe button for access to videos posted by the Chapter!

**Connecting ALS Podcast** To access current and archived episodes of this podcast from The ALS Association, click or enter <https://www.connectingals.org/episodes>

## **Advocacy in Action**

Every year, hundreds of advocates from across the country come together to talk about ways to advance public policies that will make ALS a livable disease while accelerating the search for a cure. But advocacy doesn't just happen once a year. It's an ongoing dialogue with public policymakers.

In fact, we're seeing advocacy in action right now. In recent weeks, more than 7,000 people have reached out to the FDA, imploring them to approve AMX0035 as quickly as possible. In June, the FDA announced that it was extending the time to review approval in light of additional data further showing that it is effective at reducing harms associated with the disease such as hospitalizations and tracheostomy.

While drug development is critical to making ALS a livable disease and ultimately finding a cure, our public policy priorities focus on the three main pillars of making ALS livable:

- Find New Treatments and Cures
- Optimize Current Treatments and Care
- Prevent or Delay the Harms of ALS

That means fully funding the ACT for ALS, which was signed into law in December, expanding federal funding for ALS research and making sure the FDA acts with flexibility and urgency in approving drugs shown to be safe and effective.

It also means making sure the federal government ensures coverage of new ALS treatments, that federal and state governments support and fund programs to help people with ALS access specialized ALS care, and that lawmakers enact public policies that will positively impact the lives of people living with ALS.

You can learn more about all our public policy priorities at <https://www.als.org/advocacy/our-priorities>.

# RESEARCH

## AMX0035 Prolonged Time to Ventilation, Tracheostomy in CENTAUR Trial

*(From ALSNewsToday.com)*

Treatment with AMX0035 significantly prolonged the time that people with amyotrophic lateral sclerosis (ALS) in the CENTAUR clinical trial did not require permanent ventilation or tracheostomy by over seven months, a new study shows. “People living with ALS often require medical interventions like mechanical ventilation as the disease progresses and impacts the muscles of respiration,” Sabrina Paganoni, MD, PhD, a professor at Harvard Medical School and co-author of the study, said in a press release. “These interventions come at a great cost, both personally and financially, for people living with the disease and developing therapies that can help delay these interventions can have a positive impact on their lives.”

The study, “Effect of sodium phenylbutyrate/taurursodiol on tracheostomy/ventilation-free survival and hospitalization in amyotrophic lateral sclerosis: long-term results from the CENTAUR trial,” was published in the *Journal of Neurology, Neurosurgery, and Psychiatry*. It was funded by AMX0035’s developer, Amylyx Pharmaceuticals. AMX0035 is an oral combination of two small molecules designed to protect nerve cells from damage. It is currently up for approval in the U.S, Canada, and Europe. The Phase 2 CENTAUR clinical trial (NCT03127514) enrolled 137 people with rapidly progressing ALS who were randomly assigned to take AMX0035 or a placebo daily for about six months. Then, 90 of 98 eligible participants chose to enter an open-label extension study (NCT03488524), where all were treated with daily AMX0035. A recent analysis of trial data suggested that AMX0035 treatment extended median survival times by over 10 months compared to placebo.

Here, a team led by Harvard scientists analyzed data from CENTAUR to examine the effect of treatment on other outcomes, namely tracheostomy (a tube inserted into the windpipe to make breathing easier), permanent assisted ventilation, and hospitalization for ALS-related procedures. With up to 35 months of follow-up, the risk of any of these events was reduced significantly in patients who were initially treated with AMX0035, by 47% compared with participants originally given placebo. Specifically, risk of tracheostomy or ventilation was about 49% lower with AMX0035, while risk of a first hospitalization was reduced by 44%. Median time spent without tracheostomy or ventilation was 7.3 months longer among patients originally given AMX0035 (25.8 vs. 18.5 months).

“In this long-term analysis of CENTAUR, the risk of key events including death, tracheostomy, [permanent assisted ventilation] and first hospitalization was significantly lower in those originally randomized to [AMX0035] compared with those originally randomized to placebo,” the scientists concluded, adding that the results “support potential added benefits of [AMX0035] on reducing health burden in ALS.”

The researchers noted that, since most of the patients originally given placebo eventually switched to AMX0035 during the open-label extension, the effects of treatment are likely somewhat underestimated in this analysis.

“We’re encouraged by the positive data that we continue to collect from the CENTAUR study on the potential benefits of AMX0035 for people with ALS, including a lower occurrence of first hospitalization based on data collected up to 35 months following administration,” said Mabelle Manuel, PhD, head of global medical affairs at Amylyx.

“These results suggest that AMX0035, if approved, may help extend the time before greater care needs arise – a meaningful benefit for those living with ALS and their loved ones,” Manuel added. “We will continue to explore other potential benefits of AMX0035 during the follow-up period and plan to evaluate its potential in other neurodegenerative diseases.”

Amylyx is now running a Phase 3 trial called PHOENIX (NCT05021536) to further evaluate AMX0035 in ALS patients. The study is currently recruiting participants at several sites in Europe, with recruiting in U.S. sites to follow.

## **Eledon's Antibody, Tegoprubart, Shows Promise in ALS Phase 2 Trial**

*(From ALSNewsToday.com)*

Eledon Pharmaceuticals' investigational antibody-based therapy, tegoprubart, safely and effectively reduces levels of inflammatory biomarkers in adults with amyotrophic lateral sclerosis (ALS), according to top-line data from a Phase 2a clinical trial. Exploratory findings suggested that lower levels of inflammatory biomarkers and whether tegoprubart's target is significantly reduced, called target engagement, were associated with slower disease progression, further highlighting the therapy's potential benefits in ALS.

"Neuroinflammation is a driving force in the [development] and progression of ALS. The ability to suppress inflammatory responses may translate into clinical benefit," Stanley H. Appel, MD, co-director of the Houston Methodist Neurological Institute, one of the trial's participating sites, said in a press release.

The results "demonstrated target engagement and a reduction in key inflammatory biomarkers in patients living with ALS," said Merit Cudkowicz, MD, the chief of the neurology department and the director of MGH's Sean M. Healey & AMG Center for ALS at Massachusetts General Hospital. "These encouraging data support advancing tegoprubart into larger clinical ALS studies," said Cudkowicz.

Tegoprubart is a lab-made antibody initially developed by the ALS Therapy Development Institute (ALS TDI) with support from the ALS Association, ALS ONE, and ALS Finding a Cure. It was brought into trials by Anelixis Therapeutics, ALS TDI's for-profit subsidiary that's now part of Eledon.

Administered directly into the bloodstream, the therapy is designed to suppress neuroinflammation by preventing two molecules at the surface of several types of immune cells — CD40 ligand (CD40L) and CD40 receptor — from interacting. By targeting CD40L, tegoprubart promotes a shift in immune T-cells from a pro-inflammatory status to a more immunosuppressive role that dampens immune responses, according to Eledon. As such, the therapy has the potential to halt damaging inflammation associated with ALS and other inflammatory conditions. Preclinical data showed tegoprubart reduced inflammation and motor neuron death, significantly delaying disease onset and extending the survival of animal models of ALS — further supporting the critical role of neuroinflammation in ALS progression.

Single ascending doses of tegoprubart were deemed safe and well tolerated in healthy volunteers and ALS patients in a previous Phase 1 trial. The therapy also showed favorable pharmacokinetics, or movement into, through, and out of the body. The Phase 2a trial (NCT04322149) evaluated the safety, tolerability, and pharmacodynamics (effects on the body) of four doses of the therapy — 1, 2, 4, and 8 mg/kg — in 54 adult ALS patients diagnosed in the previous two years. Participants, enrolled at sites in the U.S. and Canada, received six infusions into the vein, given every other week for 12 weeks, or about three months.

The trial's secondary measures included target engagement and changes in inflammatory biomarkers. Monthly changes in disease progression rate, as measured with the ALS Functional Rating System-Revised (ALSFRRS-R) scale, were also assessed as an exploratory goal. These were compared to disease progression of a control group of patients from the ALS PRO-ACT database, the largest ALS clinical trial dataset to date.

Newly announced top-line results showed that tegoprubart was generally safe and well tolerated at all doses, with treatment-related side effects reported in 35.2% of patients. None were serious or severe. Tegoprubart's higher doses (4 and 8 mg/kg) showed effective target engagement, based on significant reductions in levels of CD40L and CXCL13, biomarkers of immune T- and B-cell function.

Before starting the medication, patients exhibited a pro-inflammatory ALS signature comprised of 32 different inflammatory biomarkers. However, treatment led to dose-dependent, significant reductions in the levels of up to 23 of these biomarkers, including TNF-alpha, MCP1, EN-RAGE, and C-Reactive Protein. Maximum declines in these biomarkers were seen after about one month of treatment. Both effective target engagement (defined as at least a 10% drop in CXCL13 levels) and high responses (at least a 10% reduction in 75% or more of inflammatory biomarkers) were associated with slower disease progression, when compared with the external control group. High responders in the two high-dose groups showed the slowest disease progression, which was 31.3% slower than that reported in the control group. These findings "reinforce the exciting potential of tegoprubart as a promising therapy for patients with ALS," Appel said.

Tegoprubart is also being evaluated as a potential treatment for other inflammation-related conditions in clinical trials. According to the webcast, the company has plans to develop a new formulation of tegoprubart that can be administered through under-the-skin injections.

# HELPFUL HINTS

## Updated Information Available Regarding How to Access Social Security Services

*(From SSA.gov)*

Nearly two months ago, on April 7, 2022, we resumed in-person service for people with and without an appointment. As we help more people in person, we want to highlight the best ways and times for your clients to access our services.

Although we encourage using our online services at <https://www.ssa.gov/onlineservices/>, if clients can't complete their business online, they can call us toll-free at **1-800-772-1213**. Our phone lines are usually less busy before 10 a.m. and from 4 p.m. to 7 p.m. local time, and later in the week, or later in the month.

While appointments are **strongly recommended**, we continue to help people without one. An appointment reduces the wait time and ensures that a client knows what documents to bring, so we can help them in one visit. If a client needs to visit their local Social Security office without an appointment, we are here to help. Our offices tend to be less busy later in the day, later in the week, and later in the month.

To learn more about our safety measures and restrictions before visiting our offices, visit our webpage at <https://www.ssa.gov/coronavirus/gethelp/>.

## Oral Care for People Living with ALS

*(From ALS.org)*

As ALS progresses, daily routines frequently change for people with ALS and their caregivers. Activities, those that were once automatic, may require either extra time and/or physical help. Oral care is one routine that can be easily forgotten.

### **Why keep the mouth clean?**

- Maintain comfort
- Reduce likelihood of bad breath
- Reduce your risk for gum disease, which can further endanger your health
- Reduce the risk of pneumonia (infection in the lungs from bacteria in the mouth)
- Maximize the pleasure associated with chewing foods and drinking liquids
- Help manage saliva which can reduce drooling or stimulate saliva flow

**Physical changes that may occur with ALS might make it difficult to keep the mouth clean. These include:**

Changes in hand/arm function may make it difficult to

- Hold a toothbrush and brush with it
- Turn a faucet on and off
- Squeeze toothpaste from a tube
- Hold floss and move it between teeth
- Open a container of mouthwash
- Hold a cup to use for rinsing
- Use a towel to wipe the mouth
- Put dentures in and/or take them out

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Changes in function of the mouth, lips, cheeks, and tongue may make it difficult to

- Clear food stuck in the mouth after swallowing a bite
- Spit after brushing
- Swish or hold water/mouthwash in mouth
- Close mouth to avoid drooling
- Keep inside of mouth moistened

Changes in function of the swallowing muscles may make it difficult to

- Clear mouth of saliva
- Eat/drink to help stimulate saliva

Changes in mobility may make it difficult to

- Receive care in a traditional dental clinic exam chair
- Perform daily oral care while sitting upright

Changes in breathing may make it difficult to

- Keep mouth moist during use of breathing equipment (such as a BiPAP®)
- Close mouth to avoid drooling

### **Things to do for daily dental hygiene:**

Brush, using a soft-bristled toothbrush, with a fluoride toothpaste (twice per day) to prevent plaque buildup and clean mouth of bacteria build up, nighttime or care is important to avoid bacteria entrance into the upper airway during sleep. Bacteria in the airway can lead to respiratory infections

- Replace your toothbrush every three to four months (Replace sooner if the bristles start to wear out or you are recovering from a cold or illness.)

Floss between the teeth (once per day) to remove food and plaque that the toothbrush may miss

Watch for good fit of dentures- with weight loss, dentures may not fit as snug

Other tools that may help:

- Toothpaste dispenser (pump or hands-free)
- Dental wipes
- Oral irrigator (ex. WaterPik®, Water Flosser, Interplak® Water Jet)
- Electric toothbrush
- Floss holder
- Tongue scraper
- Dry mouth oral rinse
- Mouth Swabs (ex. Toothette®- for moisture relief)
- Portable oral suction device
- Suction toothbrush (ex. Plak-Vak®)
- Other adaptive equipment (ask for an evaluation by an Occupational Therapist)

### **Get Regular Check Ups**

Continue visits to the dentist once every six months

Update your medical history with the dentist's office

Discuss physical accommodations with the dentist's office

- For instance, can the dental office space accommodate a wheelchair?
- Often wheelchairs that recline or tilt may be used for exams and cleanings instead of having to transfer to the traditional exam chair
- assure that the dentist can adapt for swallowing impairments to avoid water entering the throat and causing coughing or choking.

**To find a special needs dentist in your area, please visit <https://www.scdonline.org/need-a-dentist-#/>**

# CAREGIVING

## Helping From Far Away

*From Caregiver.com)*

Because Americans have become such a transient culture, adult children are now finding themselves having to deal with an ever-growing crisis: taking on the new-found role as long-distance caregiver.

According to AARP, the typical annual total is \$7,242. On average, family caregivers are spending 26% of their income on caregiving activities. Along with the financial costs, there's also the cost of time. About 80% of all long-distance caregivers are employed, and of this, at least 44% of them have had to rearrange their work schedules, with the other 36% of them having to miss an average of 20 hours of work each month in order to conduct caregiving duties.

These costs may even be higher among those long-distance caregivers who worry about people in rural areas, where it is not so easy to have a community agency check-up on them. How do you not only juggle the caregiving duties of a long-distance nature, but how can you be sure that relatives in rural areas are getting the care that they need? In this case, you're not only dealing with distance, but you're also dealing with isolation.

When caring from a distance for a person who lives in a rural area, you must first realize that certain services in these communities will not be as abundant as those in metropolitan areas, due to a much smaller population. However, living in a rural setting can actually have an advantage - the closeness which exists among the people in these communities is genuine and strong - this can be a very valuable resource. When you visit your loved one in their rural setting, it's important for you to get to know their neighbors and friends. By engaging with this community, you'll also be able to make sure that your loved one won't be isolated when you are unable to be there. Attend as many community events with your loved one as you can, such as fairs or church functions. Check with local churches, community centers, and local service clubs in order to learn about volunteer and support services which may benefit your situation.

Getting a care manager can also help decrease the pressure that's on you, since they can work with services available in your loved one's area, like personal support, nursing services that can come to their home, delivery of meals, in-home foot care (important for those with diabetes), as well as help with personal hygiene. When you return to your own home, be sure and stay in touch with the friends and neighbors you've met. Talking to them will make you feel less guilty about not being there, and also less afraid for your loved one's well-being.

Investigate the options for a medical alert system for your loved one's home. This will allow 24 hour assistance for your loved one in the event of an emergency; it may be a good idea to leave a key to your loved one's home with a friend or neighbor so that they have quick and easy access to your loved one in case of an emergency; when you're back on a visit, plan to meet with the care providers involved, and have them bring you up-to-date with your loved one's progress; create a "communication book" where care providers can make note of concerns or questions for you, then you'll have the ability to follow-up on a weekly basis; prioritize the tasks that you want to accomplish with each visit; in order to stay focused and less confused on visits, keep a list of people you'll need to speak with; and make sure that care providers know where and how to reach you, where ever you may be.

Here are some other helpful tips:

- **Research travel alternatives** - be prepared to "care commute" at all times. Investigate travel options in advance. If you'll be utilizing your car most of the time for these visits, keep your car in good repair, and check on the route and weather before traveling. If you have to rent a car, look for the best rates. Remember, you don't have to pay for rental insurance if you already carry full coverage, or if your credit card company offers coverage. You may get a discount when buying bus or train tickets if you disclose that it's an emergency.

Know to purchase airline tickets seven days in advance and stay over a Saturday night.

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● **Discuss legal and financial issues** - these topics may be difficult to talk about, but they help ensure that the older person maintains decision-making authority even when incapacitated. Preplanning will also lessen family disagreements and protect family resources. Such issues include information concerning a will, a power of attorney, a trust, if there's going to be joint ownership, is a representative payee needed (a caregiver who receives government checks for an older person unable to manage money), and information concerning Medigap insurance.

● **Take care of necessary paperwork** - know where to find all legal, financial, and insurance documents, including birth certificates, social security cards, marriage or divorce decrees, wills, and power of attorney before an emergency happens. Also, know where to find bank accounts, titles, sources of income and obligations, and auto, life, homeowner's, and medical insurance papers. Review these documents for accuracy and update them if necessary. Store documents in a secure place such as a safe-deposit box or a fireproof box. It's always a good idea to make duplicate copies of everything.

● **Contact the aging network** – if appropriate, contact the local department on aging in your relative's community. This agency can help you identify helpful services, including obtaining a care worker. Use the National Eldercare Locator Service to find local aging agencies.

● **Create a plan of care** - if at all possible, try to gather the family together for a meeting with the person who is in need of caregiving. Find out directly from that loved one what their immediate needs and concerns are, and work on getting them the assistance they need. Summarize your agreement in writing among all the family members who are involved. Keep in mind that family difficulties are typical. You may need to bring in a family therapist or social worker to help.

Once you've had enough time to really assess what the true needs of a loved one are, you'll probably be able to create a really solid plan of action and care for them, even though there may be thousands of miles between you. Planning for the future, continually gathering information, and taking care of what's needed right now are the three main areas of focus for a long-distance caregiver, and while it may be stressful, it's not impossible, especially if you remember that you don't have to take this walk alone.

### **Needs Assessment**

- Help with chores, laundry, yard work and household maintenance.
- Help with grocery shopping.
- Need for meals delivered to the home or fixed and served there, with clean-up included?
- Is help needed with personal care, such as getting dressed or bathing?
- Do they need transportation to places important to your relative, such as church or social gatherings, the pharmacy and doctors' appointments?
- Is assistance needed with medical appointments, and/or consultation with doctors and other health professionals?
- Do they need assistance with paying the bills, banking, budgeting or other money matters like looking into financial assistance to make ends meet?
- Is it time to get a referral to an attorney experienced in elder law issues?
- Help with dispensing of medications and ensuring they are taken on time?
- Have a safety inspection of the house (test smoke alarms, look for uneven flooring, loose rugs, lighting) in order to decrease in-home dangers.
- Install grab bars or ramps to make the home safer and easier to navigate.
- Arrange for trips out of the house, perhaps to an adult day care or senior center.
- Utilize the network of friends and neighbors in the rural community who can make sure on a weekly or even on a daily basis that your loved one is well.
- Arrange for additional social visits from friends, family and other care provider volunteers.

# COMMUNITY OUTREACH & CHAPTER EVENTS

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## How to Make Donations

Credit card donations can be made to your fundraising page through our secure site. Checks should be made payable to The ALS Association Central & Southern Ohio Chapter and **include a note with your name and team**. Please mail to: 1170 Old Henderson Rd, Suite 221, Columbus, OH 43220.

## Host a Fundraising Event to Support Your Team

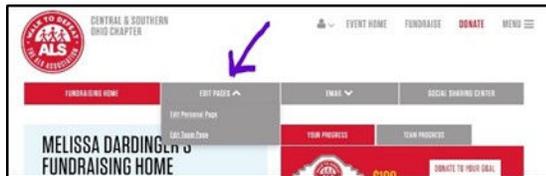
Many people have fundraising events throughout the summer to support their Walk teams. These have included charity nights at restaurants, golf outings, book sales, garage sales, and more. If you decide to hold an event, let us know what you're planning and we'll help you promote it to the Chapter. Remember, every gift counts!

## Earn Walk Swag

Earn more Walk swag with the **Key to Defeat ALS Club**. Go to [bit.ly/2022WalkToDefeatALS](https://bit.ly/2022WalkToDefeatALS) to see how. Plus, gift card donations and other prizes are rolling in from area restaurants and business to help you make the most out of Team Week.

## Personalize Your URL

Log in to your personal page, click Edit Pages, and click Edit Personal Page in the drop-down menu. Then click Edit Your Personal Page URL at the top above your name. Type in your preferred link, and voila – it's that easy!



## Still Want to *Walk Your Way*? No Problem!

If you're not comfortable attending one of the large walk events, you can still Walk Your Way in your own neighborhood or community park. Be sure to share and post pictures of your walk and use the hashtags #WalkToDefeatALS and #ALSInThisTogether. Follow along on Instagram, Twitter, and Facebook @ALSOhioCnS. Check out the full Walker Handbook for more information on how to make your walk as successful as possible.

## Download the Walk To Defeat App

Already have the app? Just download the update! Don't have the app yet? Simply go to the app store on your phone and search ALS Walk.

## Volunteer on Walk Day

Volunteers are critically important on Walk Day – we can't do it without you! Volunteer opportunities include registration, food and beverage, set-up, breakdown, and more. Please consider volunteering for all or part of the day! Contact Amy Hall at the Chapter Office to learn more about volunteer roles and how you can help.

Please let Amy know if she can be of help with your questions or pre-Walk fundraising activities. You can contact her at [ahall@ALSOhio.org](mailto:ahall@ALSOhio.org) or by phone at 614-273-2572, ext. 101. Together, let's make this the best year ever as we stride toward a world without ALS!

# COMMUNITY OUTREACH & CHAPTER EVENTS

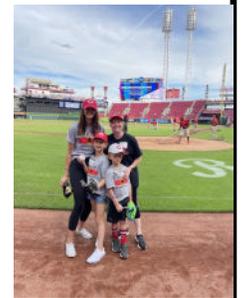
## Lou Gehrig Day with the Cincinnati Reds a Huge Success!



Our party deck was nearly sold-out for the Strike Out ALS event at the second annual Lou Gehrig Day with the Cincinnati Reds on June 2<sup>nd</sup>! The atmosphere was electric as Chapter families saw each other in person again for the first time in more than two years.



Great American Ballpark did a fabulous job on the menu – a delicious buffet dinner with Montgomery Inn barbecued pork and chicken, macaroni and cheese, popcorn, peanuts, soft drinks, beer on tap, and cookies. The Reds donated a variety of signed items to the Chapter that we raffled off at the event. These signed baseballs and player portraits, bobble heads, and tickets to future games raised an additional \$653 for the Chapter!



To spread awareness about the Chapter, our volunteers handed out custom Lou Gehrig baseball cards at each entrance to the park, promoting Chapter services and our upcoming Walk to Defeat ALS events.

By the time this newsletter is in your hands, our Strike Out event with the Columbus Clippers will also have taken place on June 18. Again, we have a sold-out crowd and expect to have a fantastic time. Be sure to buy tickets early next year for these exciting events!



## Fight Against ALS Takes to the Streets

Advocates in the fight against ALS are literally taking the fight to the streets by sporting the new sunflower-themed DEFEAT ALS specialty license plates! Join these wonderful advocates by getting your own DEFEAT ALS plate through your local Ohio BMV, and help us spread awareness every time you drive.



Steve Studebaker's Plate

Debbie Lower's Plate

Jeanne Huddleston's Plate

Shelly Few's Plate

# COMMUNITY OUTREACH & CHAPTER EVENTS

## Get Your Chapter Merchandise for Summer Today!

This summer, wear your passion for fighting ALS on your sleeve (or your head, or wrist!) with Chapter-branded merchandise. T-shirts, hats and visors, cinch sacks, wristbands, umbrellas, magnets and more can be found on our website at [https://bit.ly/chapter\\_store](https://bit.ly/chapter_store).



## EAT TO DEFEAT ALS

LET'S TAKE A BITE OUT OF ALS!

*Dayton*  
FOOD TRUCK  
ASSOCIATION'S  
2ND ANNUAL  
FOOD TRUCK  
RALLY FOR  
ALS

Honoring Chef Paul Miracle

**JULY 23, 2022**  
**3PM-9PM**  
**NORTH PARK**  
195 TAMARACK TRAIL  
SPRINGBORO, OH  
45066

6-8 PM concert  
with  
Alexis Gomez

**ALS**  
ASSOCIATION  
Central & Southern  
Ohio Chapter

### 5TH ANNUAL RACING MOWERS & KARTS

*MOW DOWN*

2 Brothers Race Way  
9068 Limerick Rd  
Chillicothe OH

- Dry camping available
- Raffles
- Food
- Door Prizes

**September 23<sup>rd</sup>**  
Practice @ 12n, Pit Party to follow. Sponsored by:  
Live from The Kraken with Dozer Dave Podcast

**September 24<sup>th</sup> - Race!**  
Gates open 8:00 a.m. Racing @ 1:00

Sponsored By:  
Elite Mower Racing, Big Dog Plaza, The Professor of Horror,  
Community Surgical Supply, Michigan Mower Racing Association,  
OMRA, CML Services, Mangie Films, Altered Minds Productions

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

# REMEMBERING

Cincinnati Area		Columbus Area		Dayton Area		Lima Area	
Catherine Johnson	6-13-22	David VanHorne	6-7-22	Robert Fortman	6-8-22		
Linda Fauber	6-3-22	Tina Filkins	5-18-22	Larry Bone	6-5-22		
				Mary Anderson	6-4-22		
				Nicholas Emrick	6-2-22		
				Jacqueline Yount	5-19-22		

# FREE FOR PALS

**RAZ Shower Chair and an Unused (NEW) extra large Bedside Commode.** Please contact Jennifer VanHorne at (614)849-8613 or email : [javh1965@gmail.com](mailto:javh1965@gmail.com)

**Reverie Queen-size Adjustable Bed Frame—with Head and Foot adjustment and Massage.** If interested, please call 614-937-8369 or 614-570-2383

**Several boxes of Ensure, New Tubing for Feeding Tube, and Suction Tips.** Please text or email me at 614-226-8152 or email: [aholly1972@live.com](mailto:aholly1972@live.com)

Metal, sectional **Wheelchair Ramp** with handrails—in good condition and a **Residential Stair Lift**.  
**Contact: Tim Cory at 614-376-8795 or email [timcory@att.net](mailto:timcory@att.net)**

**DeVilbiss 7305P-D Suction Unit** (disposable parts replaced), **Roscoe Rite-Neb4 Nebulizer**, **Pulse Oximeter**, **CallToYou Call Button & Remote Alarm**, **Disposable 60 ml Syringes** (30) 7.2 oz containers **Nutrisource Fiber Supplement** (4), nine cans of **Nutren 2.0**  
**Contact Mike at (740) 587-7729 or email [mvagengle@yahoo.com](mailto:mvagengle@yahoo.com)**

**Lift Chair**—4 years old, excellent condition. Located in the Bexley area; needs to be picked up. If interested, call **Matt at (614) 937-8369**

**Nomad MoLift Electric Lift System by Etac and an Electric Hospital Bed**—Located in the Springfield OH area. Lift needs to be disassembled from walls.  
**Contact Marty at [martybh60@gmail.com](mailto:martybh60@gmail.com) or call/text at 937-561-5952**

**INVACARE** Brand wheeled shower/commode chair with cushion and **DRIVE** Brand manual Hoyer Lift; hardly used with slings **Contact: James at (380) 222-1700**

# FOR SALE

**Hill-Rom Bed** with Hill-Rom Wound Care Mattress \$2,500. **F3 Permobil Power Wheelchair** \$3,500. **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**

**Amy Systems Alltrack M3 Wheelchair (6/22)** with battery & charger, reclines, very nice, asking \$500.00  
**Contact Karyl Woolery by phone or text at 937-344-1479**

**Quantum Q6 Edge Power Wheelchair (7/22)** many accessories included. Asking \$2,500.00  
Please **Contact Barb at (937) 763-2564** If no answer, please leave a message

**The Volkner Turning System (6/22)** MARK 1 Mattress Overlay Air, includes a machine pump and mattress, asking \$900. **Golden Lift Cloud PR512** power-lift recliner, grey faux leather fabric, non-smoking house, Excellent Condition, \$700. OBO  
**Please contact Kaitlyn via text or calling and leaving a message at (740) 649-9047.**

**2016 CHRYSLER Town & Country Conversion by Braunability (5/22)** Vehicle mileage 11,260, lowered floor power sliding doors, power folding side ramp, power kneeling system, remote entry, remote start, step & roll driver and passenger seats, rear entertainment system. Wheelchair floor lock system. Always garage parked. The van has been regularly maintained, and is currently under Mopar Vehicle Protection policy. **Permobil F3 Corpus Heavy Duty Wheelchair** – ROHO Dry Floatation Wheelchair Cushion, docking base with locking bracket installed on chair, charger. Tilts, reclines/leg/seat lift; every part is adjustable, can be controlled from armrest or back of chair. Multiple extra support accessories (headrests, head supports, lateral supports, Asking \$35,000 for both Van & Chair together. Non-smoker. Located in Westerville, OH  
**Contact: Scott via text or leave a message at 303-335-0088**

**Theracycle 300 Motorized Physical Therapy Bike (5/22)** Specifically designed to help people with movement disorders like Parkinson's disease. Hardly Used. Asking \$4500 OBO  
**Contact: Lori McCoy at (740) 412-2740 or email loribmccoy@aol.com**



# Caregiver & Survivor Groups

<b>CINCINNATI CAREGIVER GROUP</b> (current caregivers only)	Tuesday July 26, 2022 1:00-2:30 pm	Open Discussion	Yvonne Dressman, LSW	The Good Shepherd Lutheran Church 7701 Kenwood Rd Cincinnati, OH 45236
<b>CENTRAL OHIO CAREGIVER GROUP</b> (current caregivers only)	Monday July 18, 2022 1:00—2:30 pm	Open Discussion Dempsey Family Resource Center, Riverside Hospital In-Person Attendance Limited	Carleen Hubbell, BS, MA Melinda McGuire, MSW	Virtual & In-Person http://v.ringcentral.com/ join/575440587 Meeting ID: 575440587 Or dial: +1 (650) 4191505 United States (San Mateo CA) Access Code/Meeting ID: 575440587
<b>CENTRAL OHIO SURVIVOR GROUP</b>	No Group This Month	A social dinner to enjoy the company of those who have experienced a loss to ALS (Dinner on your own)	*Please RSVP to Carleen Hubbell <a href="mailto:chubbell@alsohio.org">chubbell@alsohio.org</a> or 614-273-2572 ext. 110	T B D
<b>CINCINNATI AREA SURVIVOR GROUP</b>	No Group This Month	A social dinner to enjoy the company of those who have experienced a loss to ALS (Dinner on your own)	Host: Mary Naylor *Please RSVP to Mary Naylor at 513-891-1475	Slatts Pub 4858 Cooper Road Cincinnati, Ohio 45242 (Private Dining Room)
<b>DAYTON AREA CAREGIVER GROUP</b>	Tuesday July 26, 2022 1:00-3:00 pm	Open Discussion	Whitney Taverna MSW, LISW, ACHP-SW	Virtual Group http:// meetings.ringcentral.com/ j/2404303722 or by phone 1(470)869-2200 Meeting ID: 2404303722#
<b>DAYTON AREA SURVIVOR GROUP</b>	ON HOLD T B D	Dinner on your Own RSVP Whitney 937-525-0930 or wtaverna@alsohio.org	Mary Helme Claire Robbins	T B D

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

DATE	TOPIC	LOG-IN/CALL-IN INFORMATION
<b>Monday</b> <b>July 11, 2022</b> <b>6:00 pm—8:00 pm</b> <b>Facilitator:</b>	<b>CINCINNATI REGIONAL AREA</b> <b>Power Wheelchairs &amp; Safe Transfers Demos</b> <b>Craig Rowitz, Care Medical &amp; Renee Loftspring, PT</b>	<b>In-Person Support Group</b> <b>The Good Shepherd Lutheran Church</b> <b>7701 Kenwood Rd</b> <b>Cincinnati, OH 45236</b>
<b>Monday</b> <b>July 11, 2022</b> <b>6:30 pm –8:30 pm</b> <b>Facilitator:</b> <b>Carleen Hubbell</b>	<b>COLUMBUS REGIONAL AREA</b> <b>Attend Virtual or In Person</b> <b>Helpful Resources Throughout the ALS Journey</b> <b>Kinsey Ludt, MSW from the OSU ALS Clinic</b>  Virtual Group <a href="http://meetings.ringcentral.com/join/575440587">http://meetings.ringcentral.com/join/575440587</a> Meeting ID: 575440587 or dial: +1(650) 419.1505 United States	<b>McConnell Heart Health Center</b> <b>3773 Olentangy River Road</b> <b>Columbus, OH 43214</b>
<b>Monday</b> <b>July 11, 2022</b> <b>6:30 PM – 8:30 PM</b> <b>Facilitator:</b> <b>Whitney Taverna</b>	<b>GREATER DAYTON REGIONAL AREA</b> <b>Exercise, Equipment &amp; Energy</b> <b>Shelly Janning &amp; Annie Libero, NRBC</b>  <u>Virtual Option Available</u> <a href="http://meetings.ringcentral.com/j/2404303722">http://meetings.ringcentral.com/j/2404303722</a> or by phone 1(470)869-2200 Meeting ID: 2404303722#	<b>In-Person Support Group</b> <b>Beavercreek Christian Church</b> <b>3009 Shakertown Road</b> <b>Beavercreek, OH 45434</b> <b>Multi-purpose Room 212</b> <b>(park in back of church) last room</b> <b>on your right from back entrance</b>
<b>Tuesdays</b>  <b>1:00 pm—3:00 pm</b> <b>Facilitator:</b> <b>Whitney Taverna</b>	<b>MID-NORTHWEST OHIO REGIONAL AREA</b> <b><i>In Person: RSVP needed by 1 week prior to group. If we do not have adequate in-person RSVPs, we will only hold group virtually. Virtual Option Available</i></b> <a href="http://meetings.ringcentral.com/j/2404303722">http://meetings.ringcentral.com/j/2404303722</a> or by phone 1(470)869-2200 Meeting ID: 2404303722#	<b>In-Person Support Group</b> <b>Amos Memorial Public Library</b> <b>230 E. North Street</b> <b>Sidney, OH 45365</b>  <b>Community Room</b>
<b>Monday</b> <b>JULY 25, 2022</b>	<b>FUTURE CHAPTERWIDE VIRTUAL</b> <b>ALS Research &amp; ALS Genetic Testing with</b> <b>Dr. Stephen Kolb &amp; Jennifer Roggenbuck</b> <b>The Ohio State University</b>	<b>Virtual Group Only</b> <a href="http://meetings.ringcentral.com/join/575440587">http://meetings.ringcentral.com/join/575440587</a> Meeting ID: 575440587 or dial: +1(650) 419.1505 UnitedStates

## 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 [www.alsohio.org](http://www.alsohio.org) – select “local services.”

## 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 from 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 ALS Association website, <http://www.alsa.org/policy/veterans.cfm>.

## 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 associated 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 6-years of age. 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.

## 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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