



# The Chapter-Link

## April 2022

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### EVENTS



vs.  
**Lake County Captains**  
**Friday**  
**May 6, 2022**  
**Gates Open @ 6:00 pm**

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**“1st Ever CEO Soak”**  
**Friday**  
**May 20, 2022**

**Fountain Square In**  
**Downtown Cincinnati**  
*See inside Pages 9-11*



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### Exciting News - 2022 Fundraising

#### Events are Back in -Person!



We are thrilled to say that, after two long years, our annual fundraising events will be in-person once again in 2022! We can't wait to see all of you again in support and celebration of everyone fighting ALS.

If you've ever been to one of our events, you know how much excitement and energy there is in the air. It's almost electric. And the momentum we generate together is a force for good in the fight against ALS.

First up are our annual Strike Out events with the Dayton Dragons, Columbus Clippers, and Cincinnati Reds. The event with the Reds is now happening together with Major League Baseball's second annual Lou Gehrig Day on June 2. Details and ticket information can be found inside this newsletter.

Most importantly, our annual Walk to Defeat ALS events are now scheduled in Cincinnati, Columbus, Dayton, and Southeast Ohio (Glouster). The team fundraising websites are now live at ALSohio.org. Please register your team as soon as possible so we can keep you informed of the great things planned for you!

If you're still uncomfortable gathering in a crowd, you can still Walk Your Way in your own neighborhoods or community parks. Register for the walk online and then let us know your plans so we can support your efforts.

Please help us fight ALS by supporting these events. People living with ALS need services each and every year, and these events raise three-quarters of our revenue.

We can't wait to see the love and support shared among all of you once again as our ALS community comes together for the first time in two long years. This community is truly like no other. Together we'll come back strong and keep the momentum going for a great year. We look forward to seeing all of you again!



### **Jennie Thompson, OT at the OhioHealth ALS Multidisciplinary Clinic, Receives the AOTA Interprofessional Collaboration Award**

OhioHealth and The ALS Association Central & Southern Ohio are proud to announce that our own **Jennie Thompson** has won the 2022 American Occupational Therapy Association Interprofessional Collaboration Award.

This prestigious national award recognizes Occupational Therapists who “*demonstrate exemplary interprofessional collaboration in order to provide client-centered care, provide innovation in health professional education, or improve health outcomes through research.*” Jennie has impacted the lives of her OhioHealth team members, staff at The ALS Association and so many patients and families as the OT in OhioHealth’s ALS Clinic. Additionally, her role as an education coordinator at OhioHealth has positively impacted the professional development of so many clinicians at OhioHealth & across Ohio. Jennie was nominated by members of the OhioHealth ALS Clinic team and will receive her award at this year’s AOTA national conference in San Antonio at the end of March. We would like to offer our heartfelt thanks to Jennie for the hard work and dedication that she has given to our patients and families living with ALS as well as congratulations for this well-deserved honor!

### **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>

#### **Addressing Respiratory Changes in ALS: Respiratory Care Video Series Now Available Online**

We are pleased to announce the addition of a new resource available for the ALS community, developed to introduce and explain the complicated topic of breathing changes in ALS. To view this video series, please go to <https://www.als.org/navigating-als/living-with-als/therapies-care/addressing-respiratory-changes>

# RESEARCH

## ALS Association Calls Out ‘Discriminatory’ Measures That May Hinder Access to AMX0035, Oral Edaravone

*(From ALS.org)*

The ALS Association has formally objected to the use of controversial measures to evaluate ALS drugs that can make it harder to find effective new ALS treatments and get them to the ALS community as quickly as possible. These measures have been identified by the National Council on Disability as being inherently discriminatory against people with disabilities.

Two new therapies, AMX0035 and an oral form of edaravone, are scheduled for FDA review this year. This is great news, but we are concerned that a review by The Institute for Clinical and Economic Review (ICER) may interfere with access to these drugs for anyone who might benefit from them.

The Association filed its objections as part of ICER’s recently closed comment period for a draft scoping document, which outlines ICER’s plans to conduct their assessment of these two ALS therapies. The Association is specifically objecting to the use of quality adjusted life years, often called QALYs, and equal value life years gained (evLYG) as the measures used to determine cost effectiveness, pointing out that neither measure adequately captures the value of life from the perspective of a person living with ALS.

“ICER’s model is built on assumptions that don’t make sense for the ALS community, that fail to capture the engagement and value of life for people living with ALS,” said Dr. Neil Thakur, chief mission officer at The ALS Association.

QALYs attempt to assign a value to a year of life lived in certain states and, as previously stated, have been identified by the National Council on Disability as being inherently discriminatory against people with disabilities, as their lives are assigned a lower quality score and are therefore implicitly deemed less worthy of being extended. Equal value life years, which represent an attempt to address objections to QALYs, do not address the quality of life that is highly valued by ALS patients by virtue of being quality-neutral. They fail to capture the actual benefit to the ALS community of a drug that could extend life by six months.

“Their approach to placing a value on additional months of life gained fails to fully capture the value of additional time with your family, of being able to see a child get married or a grandchild graduate from college – the things that truly give life meaning,” Thakur said.

The Association is also objecting to ICER’s failure to include the cost of medical and supportive caregiving in framework for their primary analysis.

The Association’s engagement with ICER is part of our longstanding fight to make sure promising treatments, like AMX0035 and Oral Edaravone, are available and accessible for people with ALS as quickly as possible.

We will keep fighting to make sure:

- All people with ALS are provided immediate, full coverage and affordable access to new therapies;
- Payors use methodologies that value the lives of all people with ALS;
- Health care utilization techniques and/or other administrative barriers that delay or decrease access to drugs for people with ALS and other neurodegenerative diseases are prohibited; and
- The use of arbitrary, discriminatory value assessments that limit access to ALS drugs, such as the use of metrics like Quality Adjusted Life Year (QALY) or the Equal Value Life Years Gained (evLYG) are prohibited.

## **ALS Association's Advice to NINDS: Move Quickly on Research**

*(From ALSNewsToday.com)*

In response to the National Institute of Neurological Disorders and Stroke's (NINDS) request for community input regarding what it should prioritize to accelerate amyotrophic lateral sclerosis (ALS) research, the ALS Association's overarching message is this: move swiftly to help patients.

NINDS, which is part of the National Institutes of Health (NIH), sought contributions in February from patients, families, caregivers, researchers, advocates, and clinicians. The agency's chief objective is to determine the community's top priorities for studies into more effectively diagnosing, treating, managing, and preventing ALS.

More specifically, NINDS sought feedback regarding perceived knowledge gaps, investigation opportunities, and which clinical trials it should prioritize, so that it can complete its strategic planning process to set its research priorities. The deadline for responses closed Feb. 11.

The ALS Association's research plan is based on funding for three key areas: finding new treatments and cures; optimizing current care; and preventing or delaying harms caused by ALS. "The ALS Association is focused on ensuring people with ALS live longer, with improved quality of life, and their loved ones are prevented from getting ALS," the organization said in a press release. Regarding the organization's top priority, finding new therapies, the ALS Association is focused on increasing research funding and the number of clinical trials, and improving regulatory science for ALS, particularly biomarkers and trial endpoints.

"We are placing these objectives above the fundamental science needed to better understand ALS, because our priority is to improve the health of people with ALS as quickly as possible," the organization's response states. "There are numerous risk factors, pathways and genes that have been identified as playing a role in ALS, and we can find more effective treatments if we place greater emphasis on testing their treatment potential quickly," it continued. "As new treatments come to clinic, the ALS community needs the capacity to rapidly test their effectiveness in the real world, and in combination with other treatments taken by people with ALS."

In terms of optimizing current care, the organization wants the NIH to focus on interventions that improve the health of patients and their caregivers, while continuing the search for disease-modifying treatments. To that end, the Association itself is focusing on optimizing the use of assistive technologies, reducing ALS complications, and increasing access to high quality care.

As for preventing or putting off harms caused by the progressive neurodegenerative disorder, the organization mainly wants to see interventions that can prevent new ALS cases, whether those interventions are achieved through medicine, behavior, or legislation.

"This has never been done before and requires the ALS community to overcome both scientific and organizational challenges," the association states.

All responses, including those from the ALS Association, will be compiled by working groups of community stakeholders that will present their findings at free public hearings on Oct. 26–27, at which time the public can provide input. Based on that input, the groups may modify their research priorities. Those priorities will be posted online for public comment before being submitted for approval to the National Advisory Neurological Disorders and Stroke Council.

"We value the work of NINDS and other research funders in the ecosystem of ALS research, and our research priorities are, to some extent, set by our unique position within that ecosystem. Still, we would encourage NINDS and the rest of NIH to focus on their mission and find ways to use research to advance the health of people living with ALS as soon as possible," the ALS Association wrote. "The urgency of the ALS patient community necessitates a very aggressive timeline — speed matters!," it concluded.

# HELPFUL HINTS

## Managing Breathing Issues

*(From ALS.org)*

As ALS causes muscles in the chest to weaken, breathing can become difficult. In fact, respiratory problems have long been a leading cause of death for people living with ALS. But there are things you can do to improve respiration and manage breathing problems as they occur. Examples include special techniques and mechanical aids that can help with breathing and coughing.

### **Breathing Techniques**

ALS breathing problems usually manifest first as shortness of breath when performing physical activities. This can often be managed by simply taking breaks between activities to rest and catch your breath, and by planning your schedule so that any physically demanding activities are spread out over the course of the day. Breathing exercises can also help. Fully expand the lungs by taking five to 10 deep breaths, with short rests in between, several times each day.

Breathing can be more difficult when lying flat, leading to breathlessness in bed and trouble sleeping. Elevating the head of the bed can often alleviate this problem. This is easy to do with an adjustable hospital-style bed. With a regular bed, it can be accomplished by stacking pillows under the head, neck and back or by placing pillows or blankets under the head of the mattress.

### **Coughing Techniques**

Coughing is important because it clears the lungs and airways of fluid, phlegm, food particles and any other foreign particles that might have been inhaled. By keeping the respiratory system clear, coughing helps you breathe easier and reduces the risk of pneumonia. ALS can make coughing difficult. Weaker chest muscles mean weaker coughs, which aren't as good at clearing the airways.

“Breath stacking” is one technique that can be used to create a more forceful cough. In breath stacking, you take a series of short breaths without exhaling, “stacking” the breaths until the lungs are full. You hold the breath briefly and then push all the air out at once with a cough.

“Huffing” or “squeeze coughing” is another technique people living with ALS can use. Huffing involves taking two deep breaths and then forcing all the air out of your lungs with a series of huffs, with both the mouth and vocal cords open. By repeating this several times, phlegm from deep in your lungs can be moved upward where it's easier to cough out.

Medications or respiratory therapy can also be prescribed to reduce the amount of material that builds up in your lungs – likewise, reducing the need for coughing.

### **Coughing Equipment**

There are mechanical aids that can help people living with ALS cough more effectively.

For example, “mechanical hyperinflation” involves using a resuscitator bag and mask to push more air into the lungs to produce a stronger cough. It's very similar to breath stacking, except for the additional equipment required and the need for a caregiver to help operate the mask. Automatic mechanical cough-assist devices push more air into the lungs and help pull the air back out to simulate a deep, natural cough.

### **Ventilators**

Mechanical ventilators can take on much of the workload when breathing itself becomes difficult. For many people living with ALS, noninvasive positive pressure ventilation, or NIPPV, is the preferred choice when a ventilator becomes necessary.

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Being “noninvasive” means that NIPPV devices don’t require any incisions; they simply deliver air through a nasal or face mask. NIPPV devices are portable and removable, so they can be used on an as-needed basis as you go about your regular daily activities.

Tracheostomy ventilation, on the other hand, is invasive. It requires a surgical opening into the windpipe at the base of the throat. Since tracheostomy ventilation bypasses the vocal cords and mouth, a speaking valve might be required to help you speak normally. Tracheostomy ventilation can either be a planned part of ALS patient care or an emergency procedure used when you can no longer breathe on your own.

To maintain more control over your care and the progression of the disease, it’s best to make decisions about the use of ventilators before they’re required. The ventilator can be added before it becomes an emergency, or an advance directive can let you dictate your own terms for what measures are taken in your care. A doctor can help you think through decisions and determine which actions or equipment will work best in managing ALS breathing issues.

### **The Jane Calmes ALS Scholarship Fund** **Will be Accepting Applications This Spring**

In addition to the physical and emotional toll faced by people impacted by ALS, the financial strain of the disease can devastate a family’s ability to plan for future expenses. Families impacted by ALS often do not have the financial means to support the pursuit of college degrees or vocational certificates. Recognizing this unmet need, The ALS Association and Mark Calmes, vice chair of the Association's National Board of Trustees, established **The Jane Calmes ALS Scholarship Fund** in honor of Mark's wife, Jane, who lost her battle with ALS in 2017. The purpose of the scholarship fund is to provide financial assistance to students pursuing an accredited college degree or vocational certificate, and whose ability to cover the costs is severely compromised as a result of their family’s financial burden of ALS.\* To be considered for The Jane Calmes ALS Scholarship Fund, an applicant must be:

- An individual who has had their finances negatively impacted due to having a diagnosis of ALS themselves, or having a parent, guardian, or family member (living or deceased) diagnosed with ALS;
- A high school senior, high school graduate, current postsecondary undergraduate student, or currently enrolled in vocational program;
  - Planning to enroll for a minimum of six credits per semester in undergraduate study at an accredited two- or four-year college, university, or vocational-technical school for the entire upcoming academic year, in pursuit of completing a degree program;
  - Able to demonstrate financial need.

Awards will be renewable up to three years or until a bachelor's degree is earned or graduation is achieved, whichever occurs first, based on satisfactory academic performance.

To learn more about how and when to apply for this Scholarship, either enter or click on the following link:

<https://learnmore.scholarsapply.org/calmesscholarshipfund/>

# CAREGIVING

## Cognitive and Behavioral Changes in ALS: A Guide for People with ALS and their Families

If you had asked doctors about ALS 20 years ago, the majority of providers would have told you that ALS only affects the motor and breathing functions of the body but that the mind remains normal. Thinking and behavior changes were observed in individuals with ALS and documented in scientific and clinical papers back in the 1800s. Despite these reports, though, early research and clinical care in ALS was importantly focused on establishing the diagnosis of the disease, identifying and testing techniques allowing early diagnosis of ALS physical symptoms, and the development of clinical trials and programs allowing individuals to live higher qualities of life with the progressive physical challenges of the disease. Within the last 20 years, and within the last 10 years particularly, thinking and behavior symptoms are increasingly recognized in people with ALS. Our knowledge is rapidly growing about how thinking and behavior are affected in ALS. Specifically, we are all learning how thinking and behavior changes impact disease course, symptom management, and decision making throughout the illness. Genetic discovery, brain imaging studies, and biomarker studies now provide tangible explanations for why changes in thinking and in behavior can be symptoms of ALS. Research on the highly variable presentation of symptoms in ALS has grown significantly and further work is underway to address how to predict who will develop thinking and behavior symptoms and how we can improve care and clinical trials for individuals with those symptoms.

The presentation of ALS varies from person to person. Some people with ALS will never develop changes in thinking or behavior. For others with ALS, there will be mild changes in how they think or behave but they are still able to function independently and make informed decisions about their care. Finally, for some people with ALS, changes in thinking and behavior are quite significant and severe such that these people are challenged to make informed decisions about their care and activities and require others to act on their behalf. Educating people about thinking and behavior changes unique to ALS helps to empower a person with ALS, to validate the experience of caregivers and family members, and to educate providers working with an affected person so that decisions are made in a manner consistent with honoring the individual's longstanding values, preferences, and desires.

### **How many people with ALS experiencing changes in thinking and behavior?**

Current research data suggest that up to 50% of people with ALS will never develop significant changes in thinking or behavior, over and beyond normal psychological reaction to diagnosis and symptoms. That said up to 50% of people with ALS will experience some degree of change in thinking or behavior, with approximately 25% of those people with ALS developing a full blown dementia.

### **What is the difference between “impairment” and “dementia”?**

Healthcare providers may refer to “impairment” or “dementia” when discussing thinking and behavior symptoms. “Impairment” recognizes that the person with ALS is acting in a way that is different than who he/she has always been but not to the extent that he/she cannot still complete activities and think through decisions as he/she has always done. “Dementia” recognizes that the person with ALS is acting in a way that is different than who he/she has always been AND he/she can no longer complete activities and think through decisions as he/she has always done. Different diseases can cause dementia. We now know that ALS can, but does not always, result in dementia. The type of thinking and behavioral impairment observed in ALS is often different than the rapid forgetting that marks the onset of Alzheimer's type dementia.

### **What do thinking and behavior changes in ALS look like?**

Different symptoms can develop in different individuals with ALS. Here are signs and symptoms commonly seen when behavior and/or thinking are impaired in ALS:

- Behavior becomes embarrassing, childlike, inappropriate, or uncharacteristic
- Person seems to have lost “a filter” with regard to making comments or expressing opinions
- Person begins eating sweets, or only one type of food to the exclusion of a more balanced diet
- Person loses table manners and begins stuffing their mouth with food
- Decreased attention to hygiene such as toileting, bathing, grooming, or changing clothes on a regular basis
- Loss of judgment with regard to making decisions or making a decision that reflects a strong departure from views the person expressed in the past
- Lack of concern for others, one's own illness and symptoms, and/or no view of the future
- Inability to concentrate or to shift focus from one activity to another
- Fixation on a single idea or activity with a need to repeat the concern or repeat the activity

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- Increased aggression
- Says “no” when means “yes,” or becomes less reliable with yes/no responses
- Feels like there is a disconnect between having the thought to move and being able to move the intended body part
- Writes or says words in the wrong order or without respect to grammar
- Thinks of the word he/she wants to use but cannot get it out in conversation
- Loss of spelling or loss of word meaning
- Says sentences that convey little meaning
- Cannot follow instructions to complete physical therapy/occupational therapy/speech therapy exercises, stretches, or guidelines such as swallowing precautions
- Difficulty remembering what he/she intends to do

Impairment in thinking and behavior within ALS can be due to the manifestation of the disease but can also relate to other factors such as insufficient breathing mechanics (too little oxygen or too much carbon dioxide), medication side effects, depression or anxiety, sleep disturbance, or pre-existing psychiatric or neurologic disease. It is important to bring any symptoms to the medical providers so that providers can begin to evaluate the cause of the impairment, particularly if there is any chance that it can be reversed.

### **Diagnosis of Cognitive and Behavioral Impairment in ALS**

In order to evaluate whether the cognitive and behavioral symptoms you see are related to ALS or another process, patients can be referred to a neuropsychologist for cognitive evaluation. The neuropsychologist will give you various paper and pencil tests to determine how you process information. You may be asked to recite as many words as you can, beginning with a specific letter of the alphabet. You may be asked to remember words or stories and say these back to the examiner. You may be asked to spell some words. The data collected are compared to normative data for people of your same age and education and compared to estimates of your longstanding level of function. This helps to determine if there is impairment and what type it could be. The neuropsychologist may speak to the person with ALS and also a caregiver or family member who knows the person well.

### **What happens after cognitive or behavioral impairment has been diagnosed?**

If insight and self-awareness is present, an impaired person can make sure that he/she attends to advanced directives and documents wishes and intentions for later on in the disease process. This is particularly important because cognitive and behavioral impairments, like other symptoms of ALS, advance with disease progression and worsen over time. If insight and self-awareness are absent, it becomes very important for family members, caregivers, and even health providers to set realistic expectations for the person. Without insight, a person cannot be expected to change his/her behavior. The environment around the impaired person must change. Expectations for the person should match the person’s ability level. If the cognitively/behaviorally impaired person starts to withdraw or starts to become agitated in the face of requests for certain action, these can be signs that the expectations of the situation exceed ability. Likewise, if a family member, caregiver, or care provider starts to experience more frustration or irritation in working with the impaired individual, then expectations of the situation may have to be simplified. In the context of dementia, speech therapists, occupational therapists, physical therapists, neurologists, and others working with the affected person should direct all education and interventions towards the caregivers and family as the affected person will not and cannot be expected to change on his/her own. Family members or caregivers dealing with frustration in the context of cognitive and behavioral impairment in ALS may benefit from supportive counseling, support groups, spiritual counseling, or increasing their own focus on taking care of themselves so that they have more resources (physical and emotional) to offer the person with ALS.

### **Recommendations for care and support of someone with ALS and cognitive or behavioral impairment:**

- Simplify communication with the affected person. Break sentences up into short phrases. Ask yes/no questions. Slow down when speaking.
- Provide supervision and accompany the person to all appointments to make sure information is accurately relayed and retained.
- Set realistic expectations for the person with ALS. If your requests introduce frustration, irritability, or withdrawal for either you or the person with ALS, your expectations need to be modified and likely simplified to meet the needs of the person’s current thinking abilities.
- Educate providers and caregivers working with the affected individual about where to set expectations for the affected person.
- Continue to enjoy relationships that bring joy and take breaks from relationships that add to stress.
- Continue to enjoy activities that bring joy and can be conducted safely. Refrain from activities that result in stress or result in risk of safety or liability.

# COMMUNITY OUTREACH & CHAPTER EVENTS



*Strike Out*  
**ALS**

**Join Us! Day Air Ballpark**

**Dayton Dragons vs. Lake County Captains**

**Friday, May 6, 2022**

Will Call Open | 5:00 PM

Gates Open | 6:00 PM

Pre-game Ceremony | 6:45 PM

Game Begins | 7:05 PM



**Each \$45 Ticket Includes:**

- Private seating in the Dragons Lair
- Buffet with food and drinks
- Dragons hat and Dragons t-shirt
- Pre-game ceremony with ALS guest throwing 1st pitch
- \$5 of your ticket price goes back to the Chapter to support people living with ALS

**2 Complimentary Tickets are available for those with ALS who are registered with our chapter. See below to reserve your free tickets.**

**Ticket Information:**

- Deadline to order is Monday, April 25, 2022. Tickets are limited.
- To purchase tickets online, visit <https://bit.ly/2022DragonsStrikeOut>. Tickets will be texted to you.
- You may also purchase your tickets by filling out this form and emailing it to Dragons Representative Eric Deutsch at [eric.deutsch@daytondragons.com](mailto:eric.deutsch@daytondragons.com) or faxing to (937) 228-2284 or mailing to: Dayton Dragons, Day Air Ballpark, POB 2107, Dayton, OH 45401. Tickets will be texted to you or mailed for an extra \$2.
- **To reserve two complimentary tickets for those with ALS, contact The ALS Assn Central & Southern Ohio Chapter, Tina Pinardi at [tpinardi@alsohio.org](mailto:tpinardi@alsohio.org) or call 866-273-2572, Ext. 100. Pick up tickets at Will Call, game night - ID required.**

**Tickets are limited! Deadline to purchase is Monday, April 25, 2022**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Email: \_\_\_\_\_

# OF TICKETS: \_\_\_\_\_ x \$45.00 (\$5 per ticket goes to ) = TOTAL: \$ \_\_\_\_\_

Check one: Cash: \_\_\_\_\_ Check: \_\_\_\_\_ AMEX: \_\_\_\_\_ Discover: \_\_\_\_\_ MasterCard: \_\_\_\_\_ VISA: \_\_\_\_\_

Card #: \_\_\_\_\_ Expires: \_\_\_\_\_ CVV: \_\_\_\_\_

**Please make checks payable to: Dayton Dragons**


 Day Air Ballpark | 220 N. Patterson Boulevard Dayton, Ohio 45402  
 (937) 226-2207 | [www.daytondragons.com](http://www.daytondragons.com) |    @dragonsbaseball 

# COMMUNITY OUTREACH & CHAPTER EVENTS

## Cincinnati's Piggest Raffle Ever Returns May 1



Cincinnati's Flying Pig Marathon returns to its May schedule this year, and that means the Piggest Raffle Ever is back, too!

**ADOPT YOUR PIG NOW** for just \$5, at <http://www.piggestraffleever.com>. Each raffle entry is a chance to win some fabulous prizes!

**How's it Work? Easy!** Purchase a raffle entry 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:** On **Sunday, May 1, 2021** they will draw a lucky winner of \$5,000 cash. If the winner purchased on behalf of the Chapter, we will also receive \$5,000 cash! You do not need to be present to win but everyone is welcome to join in race weekend!

## First-Ever CEO Soak



**May 20, 2022 at Fountain Square in downtown Cincinnati**

Inspired by the viral success of the ALS Ice Bucket Challenge in 2014, the CEO Soak is the “grown up” version of this engaging event.

Executive leaders that commit to being a “Soakee” will raise awareness and funds for ALS patient care, research and advocacy – providing critical support to ALS families.

It will all culminate at Fountain Square in downtown Cincinnati where the Soakee will be drenched while in their work attire.

Each “Soakee” is encouraged to engage their networks to raise at least \$2,500 for their team. This is a great incentive to engage your employee base along with your personal and professional networks. Who wouldn't want to help their boss fundraise to see them get soaked? Visit our website to learn more about how to participate and the benefits of sponsorship.

## 2022 Walk to Defeat ALS is Back in-Person!

**Websites now live to register or donate**

After two long years, our annual Walk to Defeat ALS events will be in-person once again in 2022! We can't wait to see all of you again in support and celebration of everyone fighting ALS. The team fundraising websites are now live at ALS.org. Please register your team as soon as possible so we can keep you informed of the great things planned for you! We have walks planned in Cincinnati, Columbus, Dayton, and Southeast Ohio (Glouster). We look forward to seeing all of you again this September and October!

# COMMUNITY OUTREACH & CHAPTER EVENTS

## HoneyBaked Hope for ALS Returns for Spring

Spring is finally here! If you're making plans with friends and family for Easter, Mother's Day, Memorial Day, or any other occasion, make your life easier with HoneyBaked® gift cards that support The ALS Association Central & Southern Ohio Chapter! Whether you need ham or turkey for a formal dinner, or ham for sandwiches at a potluck, we've got you covered.



**From March 1 – April 30, the HoneyBaked Ham Company will donate 20% of your gift card purchase to the Chapter to provide free services for people with ALS. You can purchase gift cards through our Chapter online, just go to [ALSohio.org](http://ALSohio.org) and click on “Get Involved” at the top, or by phone by calling the Chapter office. You can choose either an E-gift card, which will be available immediately, or a physical card that will be shipped to you free within 5-7 days. What’s more, your cards can be used at any time, not just during the promotional period.**

Don't wait! Order yours today. If you have any questions or would like to buy gift cards by phone, please call our Chapter office toll free at 866-273-2572 or in Columbus at 614-273-2572.

Thank you for your participation. Your purchase of HoneyBaked® Ham gift cards brings help and hope to hundreds of people living with ALS in our community.



## Cincinnati International Wine Festival Returns May 19-21

### **Volunteers needed to represent the Chapter**

Cincinnati's premier wine event is back in-person, and that means we need your help!

The 2022 Cincinnati International Wine Festival (CIWF) will be returning to the Duke Energy Center **May 19-21** and tickets are now on sale! This is a fun opportunity for you to have a great time tasting exotic and international wines, and support our Chapter while you're at it. Visit the [Cincinnati International Wine Festival](http://CincinnatiInternationalWineFestival.com) website for an unforgettable night for a great cause.

Additionally, as a charitable beneficiary our organization is asked to provide six to eight volunteers for the weekend. Can you help? Grab a friend and sign up for a volunteer shift at [www.wguc.org/winefestival](http://www.wguc.org/winefestival). Volunteers must be age 21 and over.

The CIWF is proud supporter of The ALS Association Central & Southern Ohio Chapter, and with your help they can provide even more grants to help us further our impact in the community. With every ticket you purchase or volunteer shift you work, you are supporting people living with ALS.

# REMEMBERING

Cincinnati Area		Columbus Area		Dayton Area		Lima Area
William Toby Marx	3-9-22	Todd Adamson	3-3-22	Violet Adkins	3-12-22	
Mary E. Wittekind	2-22-22	Nancy Hornyak	12-12-21	Susan Truesdell	2-25-22	
Angie Biesenbender	2-11-22			Sandra Combs	2-20-22	
				Judy Mann	2-12-22	

# FREE FOR PALS

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

**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

**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

**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](mailto:loribmccoy@aol.com)

# Caregiver & Survivor Groups

<p><b>CINCINNATI CAREGIVER GROUP</b> (current caregivers only)</p>	<p>No Group This Month</p>	<p>Open Discussion</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 18, 2022 1:00—2:30 pm</p>	<p>Open Discussion</p>	<p>Carleen Hubbell, BS, MA Melinda McGuire, MSW</p>	<p>Virtual Group 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><b>CENTRAL OHIO 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>*Please RSVP to Carleen Hubbell <a href="mailto:chubbell@alsohio.org">chubbell@alsohio.org</a> or 614-273-2572 ext. 110</p>	<p>T B D</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>Hosts: 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>DAYTON AREA CAREGIVER GROUP</b></p>	<p>Tuesday May 24, 2022 1:00-3:00 pm</p>	<p>Mindfulness</p>	<p>Whitney Taverna MSW, LISW, ACHP-SW</p>	<p>Virtual Group http://meetings.ringcentral.com/j/2404303722 or by phone 1(470)869-2200 Meeting ID: 2404303722#</p>
<p><b>DAYTON AREA SURVIVOR GROUP</b></p>	<p>No Group This Month</p>	<p>Dinner on your Own RSVP Whitney 937-525-0930 or wtaverna@alsohio.org</p>	<p>Mary Helme Claire Robbins</p>	<p>The Pub Restaurant @ The Greene 39 Greene Boulevard Beavercreek, OH 45440</p>

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

DATE	TOPIC	LOG-IN/CALL-IN INFORMATION
<b>Monday</b> <b>April 11, 2022</b> <b>6:00 pm—8:00 pm</b> Facilitator: Yvonne Dressman	<b>CINCINNATI REGIONAL AREA</b>  <b>Open Discussion</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>April 4, 2022</b> <b>6:30 pm –8:30 pm</b> Facilitator: Carleen Hubbell	<b>COLUMBUS REGIONAL AREA</b>  <b>Now What? : Coping and Conversations</b> <b>for pALS, Caregivers, and Loved Ones</b> <b>Eric Lichtenfeld, LISW, MSW</b>	Virtual Group 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)
<b>Monday</b> <b>April 11, 2022</b> <b>6:30 PM – 8:30 PM</b> Facilitator: Whitney Taverna	<b>GREATER DAYTON REGIONAL AREA</b>  <b>Estate Planning, Medicaid &amp; Legal Considerations</b>  <b>Nancy Roberson, Roberson Law Firm</b>	<b>In-Person Support Group</b> <b>Beavercreek Christian Church</b> <b>3009 Shakertown Road</b> <b>Beavercreek, OH 45434</b>
<b>Tuesday</b> <b>April 5, 2022</b> <b>1:00 pm—3:00 pm</b> Facilitator: Whitney Taverna	<b>NORTHWEST OHIO REGIONAL AREA</b>  <b>Respiratory Changes &amp; Devices Demo's</b>  <b>Bob Westendorf, RRT, Ohio's Hospice</b>	<b>In-Person Support Group</b> <b>Amos Memorial Public Library</b> <b>230 E. North Street</b> <b>Sidney, OH 45365</b>
<b>Monday</b> <b>April 25, 2022</b>	<b>FUTURE CHAPTERWIDE VIRTUAL</b>  <b>Therapy Throughout the ALS Progression</b> <b>with The Perlman Center ALS Team</b>	Virtual Group Only <a href="http://v.ringcentral.com/join/575440587">http://v.ringcentral.com/join/575440587</a>  or call in: (650) 419-1505 Access Code/Meeting ID: 575440587

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

As we head into the winter months, the Chapter has decided to restart indoor Education & Exchange and Caregiver groups in certain areas, based on requests that we have received from families. In order to maintain safety for our ALS patients, the Chapter will have strict requirements for any in-person group attendees, including proof of Covid-19 vaccination, masks, and social distancing. Your group facilitator will provide you with detailed guidelines for anyone wishing to attend an indoor group. Group facilitators are working on finding venues that will provide adequate spacing for participants and will contact you if an in-person, indoor group is possible in your area. 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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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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