



The Chapter-Link

May 2022

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VOL XIV ■ ISSUE 5
PUBLISHED MONTHLY



EVENTS 2022

**Big Games
Coming Up !**

* * *

Eat Pizza

*Raise Dough
at Dewey's*

* * *

See Details

Inside Pages 9-11



Announcing the DEFEAT ALS Ohio Special Interest License Plate



We are excited to announce that, after many years of hard work, the Defeat ALS Ohio Special Interest License Plate is now available! **This exclusive plate costs \$35 above the regular fee; of that amount, \$25 goes directly to the Chapter to support people living with ALS.** Show your support for The ALS Association Central & Southern Ohio Chapter by purchasing your plate at either your local Ohio BMV or online at oplates.com.

As one of our E-Newsletter subscribers, you're getting an exclusive "First Look" at this new offering. We will share the new plate with the general public throughout May for ALS Awareness Month.

This plate is the result of a years-long extensive collaboration between the Chapter and its counterpart, the Northern Ohio Chapter. In fact, we began the process all the way back in 2004, when requirements to obtain a specialty license plate were much harder to obtain than they are today. A petition was created, and over time staff and volunteers collected 550 signatures of people committing to purchase the plate – well short of the 1,000 needed by the state.

Over the years the State began easing the requirements to obtain specialty plates, and in 2019 we were thrilled to learn that our Chapters met the qualifications! Next, State legislators who are friends of our cause introduced the ALS specialty license plate proposal to the state legislature who then passed it as a bill.

We thank everyone who worked so hard to make this possible, especially current and former PALS Rob Harklau, Shelly Few, Becky Rottier, Shirley Schmelzle, and Dennis Ursetti, along with family member Robert Palladino.

We also send our thanks to the Ohio legislators who introduced the bills to make the plate possible: State Senator Stephanie Kunze, former State Representative Ryan Smith, State Representative Tracy Richardson, State Representative Adam Miller, and State Representative Jay Edwards. Also special thanks to former State Representative Anthony DeVitis for being a staunch supporter of the legislation.

Highlights:

Caregiving	7
Chapter Events	9
For Sale	13
Helpful Hints	5
Remembering	12
Reminders	16
Research	3
Support Groups	14

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. 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](#)

The Jane Calmes ALS Scholarship Fund **Will be Accepting Applications Until May 18, 2022**

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/calmescholarshipfund/>

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>

RESEARCH

Brain Implant Allows Paralyzed ALS Patient to ‘Speak’ With Family Again

(From ALSNewsToday.com)

A novel system that involves electrodes implanted in the brain allowed a 34-year-old man with amyotrophic lateral sclerosis (ALS) who had completely lost the ability to move voluntarily — known as a “locked-in” state — to communicate with his family again. Using the system, the man was able to actively participate in decisions about his own care, and to tell his young son, in his own words, that he loves him.

His case was described in the study, “Spelling interface using intracortical signals in a completely locked-in patient enabled via auditory neurofeedback training,” published in *Nature Communications*. The man was diagnosed in 2015, at age 30, with a fast-progressing form of ALS. By the end of that year, he had lost much of his ability to walk and talk. He initially retained an ability to voluntarily move his eyes, and he used eye-tracking technologies to communicate.

“In the ALS community, we typically think of people who are locked-in as being unable to move their body with the exception of their eyes,” Neil Thakur, chief mission officer for the ALS Association, said in a press release. “Some people with ALS are very proficient at using their eyes to communicate at a very high level with the help of assistive technology, such as eye-gaze machines,” added Thakur, who was not directly involved in this study. By 2017, the man could no longer fix his gaze and continue to use eye-tracking technologies. No other way, until now, existed for people with this extremely advanced disease form to reliably communicate. The patient’s family gave researchers permission to place two implants in the man’s motor cortex, the brain region responsible for voluntary movement. Each implant is about a tenth of an inch in size, and contains 64 needle-like electrodes to detect electrical signals from firing nerve cells.

Over the course of several weeks, the patient learned how to modulate his brain activity in a way that could be picked up by the electrodes and reliably used for communication. Essentially, the patient altered his brain activity by instructing his body to move. Even when such movement is no longer possible, detectable electrical signals still occur in the brain. Using these signals, the patient would modulate an auditory tone to move up or down, allowing him to answer yes or no questions. This system was then combined with a speller: the speller would read letters aloud, and the patient would select letters via the yes/no system to spell out words and communicate. To ensure the system was working as intended, the man started by spelling out pre-defined words. Within the first three days of the speller’s use, he was able to spell his own name correctly, as well as his wife’s name and the name of their 4-year-old son.

“It shows that you can write sentences with the brain even if you are completely paralyzed without any eye movement or other muscles to communicate,” said Niels Birbaumer, the study’s lead researcher and director of the Institute of Medical Psychology and Behavioral Neurobiology at the University of Tübingen, in Germany.

The system was relatively slow — on average, the patient spelled at a rate slightly slower than one letter per minute — and independent observers judged that his output was intelligible for 44 of the 107 days the speller was used during the study. Less than four months after the implant, the man moved to free spelling to express his thoughts and to participate in decisions about his care and comfort.

For example, on several occasions he used the system to request that his head or limbs be adjusted, or to ask for different types of food. He could also say when he wanted to wear socks, but not a shirt, to sleep at night, and to ask that his caregivers put gel on his eyes more often. The system also gave him a voice to express his wants beyond medical care: on one day, he used the system to say “I would like to listen to the album by [the band] Tool loud.” He also gave suggestions to improve his speller performance: “turn on word recognition,” or “tell Alessandro [Tonin] I need to save, edit, and delete whole phrases.”

It also gave the patient a voice with which to connect to the people around him. One of the first times he freely used the spelling system, he took the opportunity to thank the researchers, saying, “first I would like to thank Niels [Birbaumer].”

And the system let the man talk to his 4-year-old son, offering to watch Disney movies together and giving him the chance to say: “I love my cool son.”

US Real-world Data Show Radicava Boosts Survival Rate

(From ALSNewsToday.com)

Treatment with Radicava (edaravone) for at least one year significantly reduces the risk of death in people with amyotrophic lateral sclerosis (ALS), prolonging their survival for about six months compared with those not given the therapy, an analysis of U.S. real-life data shows.

“Real-world data may provide additional insight into treatment for rare diseases like ALS, which can sometimes be challenging to research and evaluate in clinical trials,” Gustavo A. Suarez Zambrano, MD, vice president of medical affairs at Mitsubishi Tanabe Pharma America (MTPA), which commercializes Radicava in the U.S., said in a press release.

These findings were presented through an MTPA-funded poster at the 2022 American Academy of Neurology Annual Meeting, being held in Seattle, April 2–7, and virtually, April 24–26. The poster was titled “Continued Intravenous Edaravone Treatment in Patients with Amyotrophic Lateral Sclerosis (ALS) Increases Overall Survival Compared With No Intravenous Edaravone Treatment: Results from a US Administrative Claims Database.”

Developed by Japan-based Mitsubishi Tanabe Pharma, Radicava works by lowering oxidative stress, a type of cellular damage thought to be one of the drivers of nerve cell death in ALS. Oxidative stress refers to an imbalance between the production of potentially harmful free radicals and the cells’ ability to detoxify them. The therapy, administered directly into the bloodstream, was approved for ALS in Japan and South Korea in 2015 and in the U.S. in 2017. The decisions were based on findings from the Phase 3 Study 19 clinical trial (NCT01492686), which evaluated Radicava’s safety and effectiveness in 137 adults with ALS in Japan.

Participants were randomly assigned to receive Radicava or a placebo for 24 weeks (about six months), after which they could choose to receive the therapy for an additional 24 weeks in the study’s open-label extension portion. Top-line, six-month results showed that Radicava-treated patients had a 33% significantly slower functional decline, as measured by changes in the ALS functional rating scale-revised scores, compared with those on a placebo.

Participants initially assigned to Radicava continued to experience slower disease progression in the extension portion, while those previously on placebo started to benefit from the therapy. Further analysis showed that patients initially on Radicava in Study 19 had a 52% lower risk of death and a 56% lower cumulative risk of death, tracheostomy, and permanent assisted ventilation, compared with those starting on Radicava six months later — though these differences did not reach statistical significance. Tracheostomy is a surgical procedure that creates an opening in the windpipe for mechanical ventilation.

Given the limited data on Radicava’s benefits in the real-world setting, MTPA analyzed the survival rate of 318 ALS patients receiving the therapy for at least one year and 318 matched patients who were never prescribed Radicava (used as controls).

All patients were enrolled in Optum’s Clinformatics Data Mart, a real-world de-identified database of administrative health claims across the U.S. for people with commercial or Medicare Advantage health insurance plans. The patients taking Radicava initiated the treatment between Aug. 8, 2017, and March 31, 2020. Controls were matched for potential influencing factors, including age, sex, race, geographic region, disease duration, insurance, history of cardiovascular disease, riluzole prescription, feeding tube use, artificial nutrition, non-invasive ventilation, and all-cause hospitalization.

Riluzole is an approved ALS therapy sold as Rilutek, Tiglutik, or Exservan, and is also available in generic forms. In both groups, 208 patients (65.4%) had a history of riluzole prescription.

As of March 31, 2021, a lower proportion of patients on Radicava than controls had died from all causes (48.7% vs. 61.6%). This translated into a 27% lower risk of death, with patients on Radicava living a median of six months longer than those not treated with Radicava (median survival of 29.5 months vs. 23.5 months).

“Utilizing rigorous statistical methodology to assess nearly four years of administrative claims data, we found that patients with ALS receiving Radicava ... survived longer than patients not treated with the drug in a real-world setting,” said Benjamin Rix Brooks, MD, an ALS specialist and the study’s “Findings from this analysis, combined with previously reported pivotal Phase 3 trial data, add to the growing body of knowledge regarding the use of Radicava,” Zambrano added. MTPA plans to continue assessing Radicava’s benefits in the real-world setting through additional research.

Based on positive interim findings from an international Phase 3 trial (NCT04165824), an oral formulation of Radicava called MT-1186 is now under review for approval by health authorities in Japan and in the U.S., where a decision is expected no later than May 12.

HELPFUL HINTS

Chapter Smart Home Program Now Available!

We are rolling out our **Smart Home Pilot Program in the Greater-Dayton area and beyond.** What started as a program that we thought would only be offered in the Dayton area - is now expanding due to us receiving additional funding - with eligibility to anyone in our 55-county region. We had an amazing Doctoral OT student from Kettering College here in Dayton help us set up the program and organize grant funding proposals, and we secured two grants from local Dayton Foundations, and one very sizable grant from an anonymous Dayton donor. Pretty amazing - we are so grateful for the generosity so we can make daily challenges easier for those of you living with ALS.

Attached and below are links to our program -- including a video link and an educational smart home program flyer, in addition to smart home kit options. Email has been sent to many of your therapists -- UC, OhioHealth & OSU clinics, in addition to NeuroRehab & CORP here in Dayton. So they should slowly 'be in the know' about this program.

Eligibility for program:

- Must have a diagnosis of either ALS or PLS
- Must live in our 55-county region
- Must be registered with our Chapter
- Must have an assessment by a qualified OT who has ALS and smart home tech experience (NeuroRehab & Balance is our core site for OT evals - but pALS are able to have evals with other OT's due to proximity of where they live)

Smart Home Options Available:

- Full starter kits for those WITH or WITHOUT Internet - Amazon Echo Show, Dot, Flex & Almond
- Accessories such as Smart light bulbs, plugs, cameras & firesticks
- ***Clients can mix and match - for a total per client of \$230***

Program Process:

- Request an order/prescription to be sent from your MD - Dr. Neel, Novak, OSU and others would be happy to send the order for you!
- The Order/Referral can be sent to NeuroRehab & Balance Center (or) your OT and/or Clinic of choice for 'OT-Smart Home Eval for ALS client for ALSA Smart Home Program'
- NeuroRehab & Balance Center - FAX: 937-401-6240
- NRBC and/or your OT/AT Clinic will schedule a visit (only 1 is necessary) for client
- Client seen by OT, OT assessment made
- OT emails or faxes order form to Chapter with recommendations of smart home equipment that will best fit your needs - if client is NOT registered with the Chapter - client is responsible for registering with us first
- Our Chapter will order materials
- Materials are to be shipped directly to client
- Our Chapter will check in with client to ensure materials are set up and working properly
- If tech issues arise, Chapter will assist or refer out for additional tech support
- One-month follow-up call will be made by Michelle Edwardson or Whitney Taverna to assess for overall satisfaction of the program

If you are interested in learning more about the Smart Home Program, please click on the link below or enter https://drive.google.com/file/d/1jJ0NnUII30v_9SKzWPCbI_Xkb4RCUP6e/view for an informational video. You may also contact Michelle Edwardson at 614-273-2572 ext.104, or Whitney Taverna at 937-525-0930.

Unique Summer Camp Opportunity for Kids and Young Adults

Hope Loves Company (HLC) is a non-profit organization that provides education and emotional support to children and young adults who have a loved one battling ALS. One of the programs they offer is Camp HLC, a three to seven day overnight retreat for children and young adults ages 6-21. It's an opportunity to have fun, to be challenged through team building exercises, and to meet other children who are in the same situation. Camp is provided for free for our ALS families by Hope Loves Company and their sponsors. All meals and activities are included. These are some examples of the experiences which Camp HLC provides:

Outdoor Climbing Wall: Students develop self-confidence through a personally challenging activity. With encouragement from trained instructors and classmates, students climb to reach their goal. There is an emphasis on personal achievement, not height climbed.

Action Socialization Experience (A.S.E., i.e. Low Ropes) :Students learn the importance of group cooperation and gain listening and teamwork skills while overcoming a series of physical and mental challenges on our low ropes course.

High Ropes Course (zip line): With trained staff, students will challenge themselves by executing the high ropes course, which includes a multi-line traverse, incline log, Burma bridge and zip line. (For ages 12+)

Ridge Hike: Take the opportunity to hike up a mountain, 1500' above sea level, and enjoy the breathtaking views and the surrounding area. Along the hike, we will discuss various points of interest.

Giant Swing: The giant swing is an activity in which the participant wears a harness and helmet, climbs a few steps up a ladder and is hooked into two cables and a rope. The participant holds onto part of the rope and is pulled into the air with the help of the other members of the group. The participant then counts down and releases the rope (still hooked onto the cables, of course) and swings through the air. This activity takes place at the edge of the lake, and although not actually swinging over the lake, the sensation is that you are swinging over the lake.

Tie Dye: Students can tie dye a t-shirt, pillowcase or any other clothing item!

Candle Making: Students create hand dipped candles, as well as discuss colonial life prior to electricity.

Night Hike: A walk in into the night opens up children's senses and perceptions to night life. Various sensory awareness activities are designed to explore the potential of the other senses in a nocturnal environment

Stream Ecology: Students will work together to discover the inhabitants of a stream habitat. Through discussion, collection, and identification, students unearth the diversity and interrelationships that are found within the stream.

Campfire: Camp staff will lead students in song and storytelling. They will sing silly songs and roast marshmallows!

Canoeing/Boating: The older children will have the chance to canoe, along with at least 2 adult volunteers. Additionally, the younger children will have the opportunity to go boating in a large, flat motorboat driven by a trained counselor

Upcoming 2021 camps and Locations:

- May 13th-15th, Fairview Lake Camp in Stillwater, New Jersey
- June 19th – 24th, Flat Rock River Camp in St. Paul, Indiana
- August 12th – 14nd, at Camp Emerson in Hinsdale, Massachusetts
- September 16th – 18th, at Camp Nageela Midwest in Ingleside, Illinois
- October 14th-16th, Camp Twin Lakes at Will-A-Way in Winder, Georgia
- November 18th-20st, Camp Campbell in Boulder Creek, California
- **HLC VIRTUAL CAMP:** July 15th-17th

For more information including how to register, please visit <https://www.hopelovescompany.org/>

CAREGIVING

Caregiver Stress

(From Caregiver.com)

More than one quarter of the adult population has provided care for a chronically ill, disabled or aged family member or friend during the past year. Based on current data, that translates into more than 50 million people! Sixty-one percent of “intense” caregivers (those providing at least 21 hours of care a week) have suffered from depression. Heavy-duty caregivers, especially spousal caregivers, do not get consistent help from other family members. One study has shown that as many as three fourths of these caregivers are “going it alone.” Is it any surprise that caregiver stress or burnout is becoming a critical issue?

Dealing with stress is not a new concept. None of us have immunity from the challenges of getting through life with the least amount of stress. Some people drink, overeat, smoke, bite their nails, yell at the cat, or retreat inside themselves when the going gets too tough. I’m sure you have your own ways of protecting yourself from the ravages of stress. I have often thought my cat has the right idea when stress enters her life. After one loud meow and an angry swish of her tail, she retreats to another room to take a nice long two-hour snooze. Bammm! The stress is gone. Unfortunately, people do not have the same luxury. Are you caught in the web of stress while being a caregiver? In the book, *Living with Stroke*, there is an interesting section on stress analysis. People list nine sentences that sum up all the different ways that stress exhibits itself in families of stroke survivors. Do any of these ring a bell with you?

- **Panic** “Ohmigod, I can’t handle this.”
- **Anxiety** “What if he needs me in the middle of the night and I can’t hear him?”
- **Denial** that leads to over-optimism “Oh, he’ll be fine. He just needs to come home.”
- **Irritability and Anger** “It’s all the rehabilitation team’s fault.”
- **Frustration** “I can’t stand one more thing going wrong!”
- **Fatigue** “I’m utterly, completely exhausted from the experience.”
- **Hopelessness and helplessness** “What’s the use? Nothing’s going to change.”
- **Guilt** “How can I be so angry at him? It’s not fair.”
- **Ambivalence** “I don’t know how I feel anymore. I can’t make a decision about anything.”

If you are a caregiver, I’m sure you find yourself nodding your head at more than a few of these stress indicators. I often say that caregiving is not something that people plan on or sign up for. It is a situation that sort of plops itself in your lap, totally unexpected. Caregivers are usually overwhelmed, untrained, and uneducated in the beginning. With time comes a sense of control that can help you through. Being out of control in any situation can knock a person off balance. Don’t be too hard on yourself as you muddle through this. You are a rookie now, but you are getting some heavy on-the-job training. Here are some tips that I have found to be helpful in getting your life in balance again.

- When well-meaning people offer to help, accept their help. Be specific in things you could use help with. Now is not the time to show the world how strong you are. You will only burn out quicker without help.
- Watch out for signs of depression. Get professional help if you need to.
- Educate yourself about your loved one’s condition. Information is empowering!
- Trust your gut feelings. I’m a firm believer in our innate instincts. If something sounds out of whack to you, keep asking questions until you are satisfied that the best care is being administered.
- Find other caregivers to connect with. There are many caregiver websites and support groups that can be found. If there are none in your area, start your own. Believe me, you need somebody to talk to that understands what you are going through.
- Be kind to yourself. Even if you only take a ten-minute walk around the block to alleviate some stress, DO IT! A caregiver with a lower stress level makes a much better caregiver. Getting enough sleep, exercise, and eating balanced meals reduces stress.
- If you are caring for a parent and have siblings, be vocal about what they can do to help. Some people are not comfortable with the day-to-day care but they might be willing to grocery shop for you, pick up meds, or do a doctor’s run or two. Don’t be a martyr. Your emotional health cannot take it. Face it and get on with it.
- Take charge of your life and continue to do things that you find relaxing or pleasurable. If a loved one’s disability always takes center stage instead of your needs, you will become a resentful caregiver. Not good for anyone.
- Write down things to keep your head uncluttered. Having ongoing lists of medications your loved one is taking will not only alleviate the stress of trying to remember what and when, but it is also a valuable tool when visiting the doctor.

(Continued on page 8)

(Continued from page 7)

- Keep your sense of humor. It's the most important tool you have and it's free. Humor can be found in the most surprising places, even hospitals and nursing homes. Laughter is good for the soul.
- Know your limitations! Don't let guilt get in the way of making the best decision for your family member and yourself. Not everyone can be a caregiver no matter how good their intentions might be. If you cannot be a caregiver due to an emotional, physical, financial or locational burden, you do have choices. You cannot help another if you yourself need help. The medical needs might warrant the need for assisted living or long term care. If you must find alternative living arrangements, make sure they are ones you can live with and serve the best interest of your loved one! Stay involved and vigilant that the care remains good.

Caregiving is a huge responsibility. Keeping the caregiver healthy— physically, mentally, and emotionally — is vital. Try to find the right balance in your life that allows you to care for your loved one while caring for yourself.

The ALS Association Central & Southern Ohio has monthly Caregiver Support Groups. If you are interested in joining, please contact your Care Services Coordinator to find out about groups in your area, or refer to page 14 of this newsletter for dates and times of Caregiver groups in your area.

Understanding Foot Drop

(From Caregiver.com)

The National Institute of Neurological Disorders and Stroke, National Institutes of Health, defines foot drop as “the inability to raise the front part of the foot due to weakness or paralysis of the muscles that lift the foot.” Muscles in the leg cannot raise the foot at the ankle, or the front part of the foot, due to paralysis of muscles that lift the foot.

Consequentially, people who have foot drop scuff their toes along the ground; they may also bend their knees to lift their foot higher than usual to avoid the scuffing, which causes what is called a “steppage” gait. Damage to the nerves and other medical disorders, including ALS, can cause this to be a permanent condition affecting one or both feet.

Toes that point away from the body when the foot is relaxed indicated foot drop. Feet and legs may feel weak; the person may have difficulty walking, or scuffs his or her toes, and trips frequently over the affected foot. To overcome or compensate, the person may lift the knees higher (step gait) so there is less chance of stumbling over the toes. The person may also slap his or her foot down with each step. In some cases, there may be tingling or numbness on the top of the foot, toes and ankle, caused by the particular way of walking, or it can be linked to an underlying cause of foot drop.

Foot drop is diagnosed during a physical exam. The doctor will ask you to walk and will check leg muscles for weaknesses and may check your shins and the tops of your feet and toes for numbness. Specific causes of foot drop determine its treatment. Supporting the foot with light-weight leg braces and shoe inserts, called ankle-foot orthotics, is a commonly-used treatment.

The peroneal nerve controls the muscles that lift the foot. Activities that compress this nerve, such as crossing one's legs, prolonged kneeling or squatting, or wearing a leg cast, exert pressure on this nerve and increase risk of foot drop. Electronically stimulating the peroneal nerve during foot fall can be appropriate for some people with foot drop. Surgery fusing the foot and ankle joint, or that transfers tendons from stronger leg muscles, is occasionally performed when there is permanent loss of movement.

Other helpful treatments include an ankle and foot brace or a splint, physical therapy and exercises that strengthen the leg muscles and help maintain knee and ankle range of motion; heel stiffness can be prevented by stretching exercise.

Due to increased risk of falling and tripping, caregivers are reminded to take precautions at home.

- keep floors clear of clutter
- avoid using throw rugs which can slip
- move all electrical cords from walkways and halls
- keep rooms and stairways properly lighted
- place fluorescent tape on the tops and bottoms of stairs

COMMUNITY OUTREACH & CHAPTER EVENTS

Strike Out 2022

ALS
ASSOCIATION
Central & Southern
Ohio Chapter

Strike Out ALS is back, and we want you to join us for the party!

Our friends diagnosed with ALS that are registered with our Chapter will receive **2 complimentary tickets** to one of these events. Please contact Tina at tpinardi@ALSohio.org or call 614-273-2572 ext. 100 to reserve your tickets.

Invite your friends and family to join you! Links to purchase tickets are below.
Let's **Sell Out the Strike Out** and fill these party decks for our first games back since 2019!



DAYTON DRAGONS vs. Lake County Captains (Minor League Baseball)

Friday, May 6, 2022

DAY AIR BALLPARK

Dragons Lair private seating

220 N Patterson Blvd, Dayton, OH 45402

Will Call Open | 5:00 PM

Gates Open | 6:00 PM

Pre-Game Ceremony | 6:45 PM

Game Begins | 7:05 PM

PURCHASE DRAGONS TICKETS - <https://bit.ly/2022DragonsStrikeOut>

Deadline to purchase is April 25, 2022



CINCINNATI REDS vs. Washington Nationals (Major League Baseball)

Thursday, June 2, 2022 **Lou Gehrig Day!**

GREAT AMERICAN BALLPARK

Tire Discounters Party Deck private seating

100 Joe Nuxhall Way, Cincinnati, OH 45202

Will Call Open | 5:10 PM

Gates Open | 5:40 PM

Pre-Game Ceremony | 5:50 PM

Game Begins | 6:40 PM

PURCHASE REDS TICKETS - <https://bit.ly/2022RedsStrikeOut>

Deadline to purchase is May 26, 2022



COLUMBUS CLIPPERS vs. St Paul Saints (AAA Minor League Baseball)

Saturday, June 18, 2022

HUNTINGTON PARK

Pepsi Party Deck private seating

330 Huntington Park Ln, Columbus, OH 43215

Will Call Open | 4:00 PM

Gates Open | 4:00 PM

Pre-Game Ceremony | 4:45 PM

Game Begins | 5:05 PM

PURCHASE CLIPPERS TICKETS - <https://bit.ly/2022ClippersStrikeOut>

Deadline to purchase is June 11, 2022

- Please bring a valid Photo ID to pick up your tickets at Will Call.
- A pre-game ceremony will be held with an ALS guest throwing out the first pitch.
- All-inclusive food and drink buffet will be provided.
- Limited-edition Strike Out ALS t-shirts and other merchandise will be for sale at the event.
- \$5 of your ticket price goes back to the Chapter to support people living with ALS.

The ALS Association Central & Southern Ohio Chapter
1170 Old Henderson Rd, Ste 221 | Columbus, Ohio 43220 | 614.273.ALSA (2572) | Toll Free: 866.273.ALSA (2572)
alsohio@ALSohio.org | www.ALSohio.org

COMMUNITY OUTREACH & CHAPTER EVENTS

EAT PIZZA RAISE DOUGH



MONDAY, MAY 23

4:00 - 9:00



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

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

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



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

COMMUNITY OUTREACH & CHAPTER EVENTS

2022 Walk to Defeat ALS is back in-person!

Websites now live to register, donate, and fundraise

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 <https://bit.ly/2022WalkToDefeatALS>. Please register yourself or your team as soon as possible so we can keep you informed of the great things planned for you! We look forward to seeing all of you again this September and October!

Cincinnati International Wine Festival May 19-21



Cincinnati's premier wine event is 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 <https://winefestival.com> 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. 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 volunteer shift you work or ticket you purchase, you are supporting people living with ALS. Thank you!

REMEMBERING

Cincinnati Area		Columbus Area		Dayton Area		Lima Area
Cheri Stair	3-29-22	Darlene Parrish	3-27-22	Steve Anderson	3-28-22	
Randy Thomas	3-18-22	James Swartz	3-19-22	Lynn Messenger	3-28-22	
		Danny Jasper	3-17-22	William Swob	3-23-22	
				Rufus Brummett	3-17-22	

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

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

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 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

Caregiver & Survivor Groups

CINCINNATI CAREGIVER GROUP (current caregivers only)	Tuesday May 24, 2022 1:00-2:30 pm	Open Discussion	Yvonne Dressman, LSW	The Good Shepherd Lutheran Church 7701 Kenwood Rd Cincinnati, OH 45236
CENTRAL OHIO CAREGIVER GROUP (current caregivers only)	Monday May 16, 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
CENTRAL OHIO SURVIVOR GROUP	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 chubbell@alsohio.org or 614-273-2572 ext. 110	T B D
CINCINNATI AREA SURVIVOR GROUP	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)
DAYTON AREA CAREGIVER GROUP	Tuesday May 24, 2022 1:00-3:00 pm	Caregiver Burnout	Whitney Taverna MSW, LISW, ACHP-SW	Virtual Group http:// meetings.ringcentral.com/ j/2404303722 or by phone 1(470)869-2200 Meeting ID: 2404303722#
DAYTON AREA SURVIVOR GROUP	No Group This Month	Dinner on your Own RSVP Whitney 937-525-0930 or wtaverna@alsohio.org	Mary Helme Claire Robbins	The Pub Restaurant @ The Greene 39 Greene Boulevard Beavercreek, OH 45440

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

DATE	TOPIC	LOG-IN/CALL-IN INFORMATION
Monday May 9, 2022 6:00 pm—8:00 pm Facilitator: Yvonne Dressman	CINCINNATI REGIONAL AREA Open Discussion	In-Person Support Group The Good Shepherd Lutheran Church 7701 Kenwood Rd Cincinnati, OH 45236
Monday May 2, 2022 6:30 pm—8:30 pm Facilitator: Carleen Hubbell	COLUMBUS REGIONAL AREA “Promoting Optimal Living at Home” Kris Parrish MOT, OTR/L, ECHM, CAPS Home Accessibility Solutions	Virtual Group Only http://v.ringcentral.com/join/575440587 Meeting ID: 575440587 Or dial: +1 (650) 4191505 United States (San Mateo CA)
Monday May 9, 2022 6:30 PM – 8:30 PM Facilitator: Whitney Taverna	GREATER DAYTON REGIONAL AREA Palliative Care & Hospice	In-Person Support Group Beavercreek Christian Church 3009 Shakertown Road Beavercreek, OH 45434
Tuesday June 6, 2022 1:00 pm—3:00 pm Facilitator: Whitney Taverna	NORTHWEST OHIO REGIONAL AREA In-Home Care Options— Home Health, Palliative Care & Hospice	In-Person Support Group Amos Memorial Public Library 230 E. North Street Sidney, OH 45365
Monday JULY 25, 2022	FUTURE CHAPTERWIDE VIRTUAL ALS Research & ALS Genetic Testing with Dr. Stephen Kolb & Jennifer Roggenbuck The Ohio State University	Virtual Group Only http://v.ringcentral.com/join/575440587 or call in: (650) 419-1505 Access Code/Meeting ID: 575440587

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

As case numbers for Covid-19 continue to decrease in Ohio, the Chapter has decided to restart indoor Education & Exchange and Caregiver groups in certain areas, based on requests that we have received from families. The former restrictions that were put in place over the last several months, including mandatory masks and proof of vaccination will be lifted. Due to the risks that Covid infection presents to people with ALS, the Chapter strongly encourages group attendees to be vaccinated and to continue masking at indoor groups. If Covid-19 cases should spike over 50/100,000 cases in Ohio, the Chapter will reinstate the former restrictions until numbers stabilize. A Chapter-wide, virtual group option will continue to be made available to anyone not wishing to attend an in-person, indoor meeting.

REMINDERS

Monthly Chapter-Link Newsletter Mailings

The Chapter-Link is mailed to all patients who are registered with the Chapter. When individuals are no longer actively receiving services through the Chapter, they are removed from the newsletter mailing list. Former caregivers and interested parties are encouraged to continue receiving the newsletter by email. Newsletters dating back to one year from the current issue area available at 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)

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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