



The Chapter-Link

June 2022

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2022 EVENTS

Cincinnati Reds
June 2, 2022

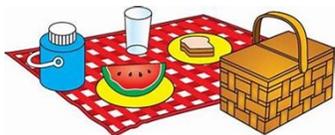
Columbus Clippers
June 18, 2022

* * * *

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

See Details

Inside Pages 9-10



Exciting Plans Taking Shape for Annual Walk to Defeat ALS®



I can't tell you how good it feels to be working on our Walk to Defeat ALS® events again this year. We are OVERJOYED to be back walking together in person!

Plans are well underway for events in Cincinnati, Columbus, Dayton, and Southeast Ohio, thanks in part to the addition of our new Events Fundraising and Engagement Manager, Amy Hall.

Amy attended Ashland University, where she majored in Theatre Education. Amy and her husband, Ross, keep busy with their three kids age six and under – and a dog. She enjoys playing tennis and pretending to play golf. She is an avid reader, lover of classic movies, Disney, Marvel, Italian food, and sweets of all kinds. She has the energy, enthusiasm, and creativity to bring our events to life!

Amy is already working directly with Walk teams and event vendors, and she's looking forward to meeting everyone and seeing all the creative ways you help to raise funds in the fight against ALS. She can assist you with personalizing your Walk page, sending out emails through the Participant Center, facilitating a corporate sponsorship or providing chapter materials for your own fundraising event supporting your team.

Registering for the Walk to Defeat ALS®, making a self-donation, and raising funds has a **direct impact** on the quality of life of those living with ALS today, by making local care and services available. Remember, there are valuable resources on your city's walk page and in the Participant Center. **Register today at bit.ly/2022WalkToDefeatALS.**

You might be surprised to learn that 1 in 2,400 people will say YES to a non-profit, but **1 in 4 say YES to a friend!** Please know that **EVERY DOLLAR COUNTS**, from the quarters at your children's lemonade stand to the thousands of dollars available through company match programs.

We could not make this happen without YOU. You are special! You are needed! You are valued! Please let Amy know if she can be of help with your questions or pre-Walk fundraising activities. She's just an email or phone call away! You can contact her at ahall@ALSoHio.org or by phone at 614-273-2572, ext. 101. Together, let's make this the best year ever as hand in hand we stride toward a world without ALS!

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](#)

Ban Discrimination Against People Living with ALS

People living with ALS urgently need effective new treatments. The Institute for Clinical and Economic (ICER) is reviewing Amylyx Pharmaceutical's AMX0035 and Mitsubishi Tanabe Pharma America's (MTPA) oral edaravone, prior to FDA approval, and will make "value assessments" on these new therapies. Their recommendations will impact decisions on cost and access to these drugs by private insurance and Medicaid at the state level and the Veteran's Administration at the federal level.

ICER value assessments could be used by Medicare in the future. ICER uses Quality Adjusted Life Years (QALY) and Equal Value of Life Years Gained (evLYG) methodology in its analysis. The National Council on Disability, an independent federal agency, has asked Congress to ban the use of Quality Adjusted Life Years (QALY) in Medicare and Medicaid because these methods discriminated against people with disabilities. We agree with NCD and oppose all discrimination against people living with ALS.

Add your name to the petition at <https://als.quorum.us/campaign/ALSdrugaccess/> to join the fight to ensure people living with ALS have immediate, full coverage and affordable access to new therapies.

Petition

We urge all insurers at the state and federal level, along with all policymakers, to:

- Prohibit the use of arbitrary, discriminatory value assessments that limit access to ALS drugs, such as the use of metrics like the Quality Adjusted Life Year (QALY) or the Equal Value of Life Years Gained (evLYG)
- Prohibit health care utilization techniques or other administrative barriers that delay or decrease access to drugs for people with ALS and other neurodegenerative diseases.
- Provide immediate, full coverage and affordable access to new therapies for all people living with ALS.

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

Radicava Oral Suspension Earns FDA Approval

The U.S. Food and Drug Administration (FDA) has approved Mitsubishi Tanabe Pharma America (MTPA)'s oral suspension formulation of edaravone, Radicava ORS, for the treatment of amyotrophic lateral sclerosis (ALS).

The oral therapy is designed to offer the same efficacy as MTPA's Radicava (edaravone) — an FDA-approved, into-the-vein therapy shown to slow ALS progression — while being more convenient and less burdensome for patients. Radicava ORS can be self-administered at home and should be taken orally or via feeding tube (5 mL/105 mg) in the morning after overnight fasting. Patients should not consume food (except water) for one hour after administration. The medication comes in a portable bottle, includes a 5 mL oral syringe for accurate dosing, and does not need refrigeration or reconstitution before administration.

Radicava ORS has the same dosing regimen as Radicava: an initial treatment cycle of daily dosing for 14 days, followed by a 14-day treatment-free period, and subsequent treatment cycles consisting of daily dosing for 10 out of 14-day periods, followed by 14-day treatment-free periods.

“At MTPA, patients have been the driving force behind our work as we strive to develop meaningful treatment options for ALS and continue to tackle unmet needs,” Atsushi Fujimoto, MTPA's president, said in a press release. “Five years ago, we proudly launched Radicava as a treatment option for patients with ALS in the U.S. Now, we continue to push the boundaries of innovation with Radicava ORS, an orally administered option allowing patients flexibility in how they take their medicine,” Fujimoto added.

“ALS is a progressive disease that, due to its [variable] nature, impacts patients at different rates with varying symptoms,” said Tulio Bertorini, MD, a professor of neurology at the University of Tennessee Health Science Center in Memphis. “Therefore, it is crucial that patients have treatment and formulation options that accommodate their own unique needs, and Radicava ORS provides [healthcare providers] who have prescribed their ALS patients edaravone with an alternate delivery option,” Bertorini added.

The FDA's decision comes about four months after the agency granted priority review to MTPA's application, shortening the review process to up to six months, as opposed to the standard 10 months. Similar applications are being reviewed by health authorities in Japan — where edaravone's into-the-vein formulation is sold as Radicut — and, more recently, in Switzerland. Developed by Japan-based Mitsubishi Tanabe Pharma, edaravone works by reducing oxidative stress, a form of cellular damage that is considered one of the drivers of nerve cell death in ALS. The into-the-vein formulation, administered through hour-long infusions, was approved for ALS in Japan and South Korea in 2015, in the U.S. in 2017, in Canada the year after, and in Switzerland in 2019. It is not available in the rest of Europe.

Regulatory approvals were based on data from the Phase 3 Study 19 clinical trial (NCT01492686), which showed that six months of Radicava treatment slowed ALS patients' functional decline by 33% compared with a placebo. The approval of Radicava ORS was supported by Radicava's efficacy data and pharmacological findings demonstrating that the oral formulation delivers similar amounts of the active medication to the body. It also was based on data from an MTPA-sponsored, worldwide Phase 3 trial (NCT04165824) that assessed Radicava ORS's safety and tolerability in 185 adults with ALS whose symptoms began within three years of enrollment. Participants received 105 mg of the therapy in the same dosing regimen as Radicava for 48 weeks (nearly one year). Interim results showed that six months of treatment were generally safe and well-tolerated. Exploratory efficacy data also suggested that the oral formulation may slow functional decline to a degree comparable to that seen with Radicava in Study 19. Those who completed the trial could enter an open-label extension study (NCT04577404), where they are receiving the therapy for 96 weeks (nearly two years). The main goal is to evaluate its long-term safety and tolerability, but exploratory efficacy measures also will be assessed.

(Continued on page 4)

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Also, two dosing regimens of Radicava ORS are being tested against a placebo in a Phase 3b trial (NCT04569084) that is recruiting up to 380 adults with ALS at 95 locations in the U.S., Canada, Europe, Japan, and South Korea. Participants must have developed ALS symptoms in the two years prior to enrollment. The trial's main goal is assessing changes in ALS Functional Rating Scale Revised scores, a measure of functional disability. Secondary goals include changes in lung function and overall health, as well as the time to death, tracheostomy, or ventilatory support. Tracheostomy is a procedure in which a tube is inserted into the neck to help with breathing. The study is expected to end in July 2023.

The most commonly reported adverse side effects with Radicava include bruising, walking problems, and headache. Fatigue was reported by 7.6% of patients taking Radicava ORS. People with a known allergy to edaravone or any of the inactive ingredients in Radicava and/or Radicava ORS should not be given these medications. According to edaravone's label, patients should notify their healthcare provider if they become pregnant or plan to become pregnant, or are breastfeeding or plan to breastfeed.

As a part of MTPA's commitment to helping patients with ALS access Radicava and Radicava ORS, the company created the *JourneyMate Support Program*, which provides resources to help patients and caregivers on their ALS treatment journey. It also provides information about insurance coverage and financial support programs for patients prescribed Radicava ORS.

"To address the unmet needs in ALS, we must continue to find new treatments, as well as optimize current treatments and care," said Calaneet Balas, president and CEO of The ALS Association. "We thank MTPA and the FDA for working diligently to make this oral formulation possible and are confident it will be a welcome addition to help further support the ALS community," Balas added.

Research Seeks to Understand Stigma and Quality of Life in ALS

People living with ALS and adult caregivers can help researchers learn more about stigma and quality of life in ALS.

Dr. Melinda S. Kavanaugh, a professor at the University of Wisconsin-Milwaukee in the United States, and Marion Sommers-Spijkerman, Postdoctoral fellow at UMC Utrecht in the Netherlands, are leading a research study into stigma, which includes things like negative attitudes or untrue beliefs about the disease, and impact on quality of life. The research is supported by The ALS Association.

They are looking for people, **living anywhere in the world**, who are:

- **Adults diagnosed with ALS/MND** – another adult may complete the survey if you are physically unable to
- **Adult caregivers** - anyone who helps care for or assist someone with ALS/MND
- Must be at least 18 years of age and older
- Must be able to read and understand English

Participation in this research involves:

- completing an online survey that asks about your experiences either living with ALS/MND

OR

- your experiences helping a family member with ALS/MND.

Your participation is completely voluntary (meaning you have a choice in whether to join), and your responses are anonymous and confidential. The survey will take about 20-30 minutes to complete.

Your feedback will help make recommendations for future programs targeting stigma in ALS.

If you would like to participate in this research survey, [click here](#) or enter <https://www.als.org/stories-news/research-seeks-understand-stigma-and-quality-life-als>.

HELPFUL HINTS

Minimizing Fatigue

(From ALS.org)

Although the course of ALS is unpredictable, fatigue is one outcome that is predictable, resulting from muscle weakness and spasticity. Fatigue can range from mild lassitude to extreme exhaustion. People often complain of tiredness, dwindling strength, and lack of energy. Despite the adverse effects of fatigue, symptoms can be minimized through effective management. By recognizing the signs of fatigue, knowing which factors worsen symptoms, and learning how to conserve energy, persons with ALS can greatly improve their quality of living. Noticeable signs of fatigue include: Slower body movement, slower speech responses, short answers, lower voice volume, dull tone of voice, shortness of breath, increased sighing, anorexia, irritability, anxiety, crying episodes, decreased smiling, lack of enjoyment of previously enjoyed experiences, decreased caring about things that were previously important, deterioration in appearance and grooming, increased forgetfulness, increased preference for being alone, and disinterest in decision making daily plans. Factors which may aggravate fatigue include: Immobility, overexertion, sleep disruption, pain, excessive weight loss, protein malnutrition, breathing weakness, stress, anxiety, hopelessness, grief, too hot or cold weather, certain medications (such as tranquilizers, sedatives, pain relievers, antihistamines, muscle relaxants), alcohol, smoking, the unavailability of people when help is needed, the lack of financial resources to provide for needs to make life easier, and an inaccessible home environment which has steps and long distances between rooms.

Anti-Fatigue strategies are:

- Learn methods of making every task easier. Use assistive devices when needed. See an occupational therapist for determining what is best for your needs. If you have trouble walking, don't resist getting a wheelchair. A motorized wheelchair will spare you the exertion of manually wheeling around in a standard model.
- Pace yourself. Move slowly and easily. Stop and rest often and take a few breathes before you start again. If you become breathless during a task, it is time to stop. Schedule heavier task during predicted times of higher energy. Plan your activities and gather everything you need before you start. Don't stand when you can sit. Utilize possible shortcuts. Obtain assistance in completing tasks if you need help. Always allow enough energy to enjoy at least one valued experience each day.
- Alternate activities with periods of rest. Schedule regular rest periods each day, perhaps a half hour after morning care and an hour in the early afternoon. Rest before going away.
- Get a handicapped parking sticker. Your local department of motor vehicles has the form that your physician will need to fill out.
- Try to establish a regular sleeping pattern. If you have problems waking up at night, determine why and what to do about it.
- Avoid prolonged bathing in warm water, as it may worsen muscle fatigue. Be cautious of extreme outdoor temperatures.
- Maintain your nutritional requirements each day, and prevent unnecessary weight loss. You may need to consult with a dietitian.
- Avoid stressful situations as much as possible. Understanding fatigue will help family members cope better with emotional upsets, realizing they are not personal attacks, but normal responses to fatigue.
- If you feel noticeably weaker or have difficulty breathing after taking a medication, let your doctor know. Perhaps your medication needs to be substituted for another one or the dosage altered. Trouble breathing, however, may be related to breathing fatigue and may warrant an evaluation by your doctor for a breathing remedy.
- Make your living environment accessible for daily activities, and promote energy conservation. Moving a bed to another location or relocating personal items are some examples.

Failure to manage fatigue can result in unnecessary suffering, social isolation and rapid physical deterioration. However, effective management will maximize your wellness and abilities, giving you the desire to keep living and the strength to carry on. Although in ALS you can't take away fatigue, you can learn to overcome fatigue and not let it overcome you.

Dressing with Ease, Style and Comfort

(From ALS.org)

Dressing and undressing are often a challenging task among people with limited mobility. While buttons and zippers are frustrating for some, others may find reaching arms through armholes or putting legs through leg holes tedious chores. Wearing accessible clothes and selecting attire to meet individual needs will make dressing easier, sparing unnecessary aggravation and fatigue.

Getting dressed everyday, even if not leaving the house, is really important for boosting self-esteem. In general, clothing should not restrict joint motion. Light-weight or stretch-knit fabrics allow greater freedom of movement. Roomy armholes and garments which open in the front, eliminating the need to raise arms over head are easier to put on and take off. Large buttons, which require little finger/hand coordination can replace standard fasteners, and be hidden in shirts, blouses, dresses and pants. Zippered fronts on tops and dresses also offer convenience. Buttons sewn on with elastic thread are easier to manage. Sewing fabric loops inside pants and underwear makes pulling them on and off much simpler. Trousers with elastic waistbands or drawstrings and French-cut underpants with wide leg openings, like boxer shorts, make dressing and toileting easier. Leg brace wearers should choose knit pants loose enough to pull on easily over braces. Wraparound skirts go on better than skirts which fasten in the back, and accommodate weight changes. Wearing a wraparound skirt with the opening in the back, as well as drop-seat pants, are ideal for using the toilet when traveling.

Some people find dressing safer and easier while lying down, especially when pulling up pants.

Others prefer to sit on the edge of the bed or chair. Those who have one side weaker than the other should dress the weaker side first. Dressing aids are available to help persons put on and take off garments. Some devices include a dressing stick with a hook on the end to assist in pulling up pants without bending over; a buttoner to pull buttons through button holes; a zipper pull to open and close zippers; a stocking aid to pull on stockings; long wooden scissors for reaching clothing; a long-handled shoehorn to help get shoes on.

What to wear on the feet depends on one's ability to walk. Persons with weak ankles and feet may warrant an evaluation by an occupational or physical therapist. Lightweight, supportive shoes may be recommended for walking, and possibly brae support too. Some persons prefer moccasins, as rubber-soled shoes may cause tripping, although they help keep the feet from slipping off wheelchair footplates. To put laced shoes on and off with ease and without having to retie them, replace standard shoelaces with elastic laces. Other kinds of easy access shoes are shoes with Velcro fasteners across the top, or loafers.

Persons who sit a lot should choose clothes that not only feels comfortable, but looks attractive while sitting. Wearing a flexible fabric, such as a soft cotton/polyester blend, moves with the body, providing the most comfort. Wearing loose tops that are worn on the outside of pants and skirts look and feel the best. Wheelchair users find short jackets, ponchos or capes more convenient than long coats. Men who wear suits may need to alter their suits, adding extra room in the shoulders and the seat. The use of clip-on ties or ready-tied ties with a Velcro fastener may spare the hassle of tie tying. Dresses and skirts that are cut fuller in the hips prevent riding up when sitting. Although outfits with fullness are comfortable, excess fullness in sleeves, pant legs, and skirts can get caught in wheelchair spokes, and can also cause tripping.

Whether a fabric is comfortable depends on how it feels, how much heat it retains, and how well it absorbs moisture. Because immobility and loss of subcutaneous fat can cause some persons to feel cold, wearing several layers of light clothing can trap in heat and is more effective in keeping warm than using heavy clothes. The wearer can remove layers when feeling overly warm. Light clothing made of terrycloth or cotton flannelette fabric may be more comfortable.

In addition to accessibility and comfort, color, and texture should be key factors in clothing choices. Colorful tops add brilliance to basic slacks and skirts. Fleecewear is both functional and fashionable, and is easy to wear anytime, anywhere. Those who like denims will find stonewashed cotton the softest. Slippery fabrics, such as those used in nylon lingerie, allow the body to slide easily from one surface to another, like from bed to chair. Wearing nylon pajamas or gowns will help the wearer turn over in bed. Persons with breathing problems may breathe better with wide open necklines, and should avoid hairy fabrics, like mohair, as floating filaments may be inhaled.

Informative links:

- Silvert's Disabled Adaptive Clothing

<http://www.silverts.com/>

- Buck and Buck

<https://www.buckandbuck.com/shop-by-need/als-clothing.html>

- Easy Access Clothing

<http://easyaccessclothing.com/>

CAREGIVING

Children as Caregivers

(by LeAne Austin, RN, Caregiver.com)

"It's my responsibility," he told me. "We're family." His name is Joel and he is 11. His 13-year-old brother, Scott, feels the same way, explaining that it's "just something you do, you take care of each other." This is not an uncommon theme in children when they live with someone who has a physical disability or a chronic illness. Whether it's a parent, step-parent, grandparent, sibling or non-relative, children also take on the role of caregivers, though this role is frequently less distinct than that played by the adults in the home.

However, children are no less affected by the life changes that come with caring for someone with illness or disability, and recognizing the effects that this situation has upon them is the key to helping young people cope with the stress and uncertainty that often accompanies it. This may be particularly challenging since much of the time the person needing care is a parent. "Disability" and "illness" can take many forms, from a sudden injury which forces changes in mobility, such as a spinal cord injury or fracture of a limb, to more insidious medical illnesses like ALS.

The way each child reacts and copes with the medical situation is largely based upon their personality and prior life experience. According to one person interviewed who was a caregiver for her mother and siblings following her father's death, "you get through it." Now a Social Worker, she feels that "those who are not 'strong enough' may go on to marry early to get out of the situation, or find themselves in unhealthy relationships" where they are dominated by a stronger personality. She also stated that "it's just what you do," and this is a common comment made by those who found themselves in a caregiving role when they were young.

Caregiving takes many forms, from helping with younger siblings to performing household tasks normally completed by an adult, such as cooking or providing personal care to the disabled or ill person. Often, the receiver of the care is an adult, which places the young person in a precarious position of being a child, essentially performing parental functions for an adult. This can result in role conflicts within the child, and changes the dynamic in the parent-child relationship. In interviewing those who had entered into the role of caregiver at an early age, it was notable that none of them initially indicated feelings of resentment at their situation. Like Joel and Scott, it came as part and parcel of being a family, but there is a cost.

Despite this apparent acceptance of their ill-defined role, children demonstrate recognizable physical and emotional responses to their situation. These can include, but are not limited to: changes in social behaviors, decline in school performance, decreased participation in previously enjoyable activities, mood disturbances, increased fatigue, personality changes and "escape" behaviors, such as self-isolation. Changes in social behaviors can be seen in the way they interact with both adults and other children. Some use more adult language, engaging adults in social situations rather than persons of their own age, while others appear to regress or demonstrate attention-seeking behaviors such as baby talking, excessive crying or thrill seeking.

School performance changes can result from preoccupation or worry about the ill or disabled person, though this is generally more prevalent at the beginning of the changes at home than when the situation is long-term. Behaviors which are disruptive in social situations affect school, as well, and the child may talk in class, become tearful, or pull pranks which land them in the principal's office, or which require that the child be sent home, as a conscious or unconscious attempt to regain their child role.

Children generally tend to be self-focused. With the addition of the illness or disability, that focus necessarily and abruptly changes to one of helping others. Rather than indulging in their usual enjoyable activities, they may decline invitations for age-appropriate activities because they need to "go home and help mom" or whoever they are assisting at home. This increased sense of responsibility, though somewhat overdeveloped due to the unique situation in which they have been placed, overtakes the drive to seek personal enjoyment. Mood swings can also be evident in some youngsters. A sense of loss of control, fear, or guilt that they may have been the cause of the illness, or if they have suffered a significant loss can manifest themselves in very strong feelings. Incidents that would not have warranted even a mild response can become gigantic and the focus of these strong emotions may result in verbalized and sometimes displaced anger. This anger is rarely directed at the object of the feelings, however, which makes it difficult to diagnose and, subsequently, challenging to address. And, as children have generally less sophisticated ways in which to communicate their feelings, they may express them as behaviors. Fatigue can be an emotional or physical manifestation, with the pressures of school, combined with greater duties in the

(Continued on page 8)

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home, and the stress of taking on a parental role in the care of the ill person. The child may not fall asleep easily, have trouble staying asleep, or wake up early, “thinking.” Personality changes can be related to sleep disturbance, internalized guilt or resentment, response to stress chemicals in the body, or a change related to how the child “thinks” they should be acting. Assuming the role of caregiver plays directly into the role-conflict—am I a child or am I an adult? Escape behaviors such as reading for hours, spending inordinate amounts of time alone in his/her room, taking long walks, or plugging in a headset is a means to get away from the demands of being a caregiver. Although not necessarily a negative behavior as it provides the child with an outlet, it can be detrimental if it adversely affects the child’s ability to relate to others or interferes with concrete interactions. Since feelings of isolation can already be present in the situation, self-isolating behaviors may reinforce the feelings of being alone and can potentially lead to significant depression, which compounds the already-present feelings of loss. Most children get through what usually amounts to a brief time of caregiving without lasting, negative effects.

Generally resilient, most children adjust adequately to the temporary life change and go on without residual problems. It is important, however, to recognize that children grieve, too, and that grief is not limited to death and divorce; life changes of every kind can elicit a grief response, which is just as powerful in children as in adults, and is generally less understood. Like adults, children grieve in their own ways. Many of the emotional and physical changes that are seen as attributed to adjustment problems or reactions to being a child caregiver are, in fact, indicators of grief. Being unable to effectively express these feelings, or lacking the ability to understand what they are feeling, increases the frustration and isolation. Former child caregivers have related that once they reached adulthood, they found themselves sometimes emulating caregiving in their personal and professional relationships. Many that I interviewed chose helping professions such as nursing, teaching or social work. This is consistent with the personality traits required of a caregiver of any age. Knowing the effects of caregiving on a child, we can better understand how to help our children cope with the intense feelings associated with living with someone else’s illness or disability.

First and foremost, communicate with the child. They need to know that they are not responsible for the adult’s or sibling’s condition. Guilt plays a significant role in a child’s desire to step into the caregiving role. Providing simple and understandable information about the condition, and answering their questions, goes a long way to resolving guilt feelings, as well as easing fear based on the “unknown.” Scott said that though he sometimes was afraid that his mother would die, he did not share his feelings with Joel. He explained, “I don’t want him to worry any more than he already does.” Scott was dealing with the “unknown,” while protecting his brother from it; however, he didn’t realize that Joel was doing the same thing. It is OK to talk about the illness or disability, but don’t make it dinner time conversation every day. Children are very aware of changes in their environment and usually know, without being told, that something is “wrong.” Talking about every ache and pain only reinforces that the parent needs “help,” and further engages the child into the caregiving mode. Instead, talk about everyday things. This reassures the child that the life they know is still going to go on, despite the change in health of their family member. Second, though it is often easy to accept the help of others when we are ill, it is vital for children in this type of household to have the adult remain as independent as possible, and that they rely on available adult help. This diminishes the role-conflict that can arise when children take on adult responsibilities. Utilize the children in performing age-appropriate tasks, such as folding their own clothes, feeding pets, taking out the trash or loading the dishwasher, and save the more adult responsibilities, such as medication administration, dressing changes, and providing personal hygiene, for the adult caregivers. Utilize outside resources to supplement in-home care to keep child caregiving to a minimum.

As difficult as it can be when illness enters into a home, there needs to be equal focus on both the needs of the child and the needs of the person who is ill. Achieving a balance between each person’s needs allows the child to focus on age-appropriate issues such as school, interactions with peers and personal growth, without nurturing feelings of guilt over not “doing more” with. Verbalizing interest in the child’s life provides positive reinforcement for development of interests outside the home. This can also help to decrease mood changes associated with fear or loss of control, as they have the opportunity to succeed outside the home environment with the support and approval of those in the home. Escape behaviors come into play when the child has to devote a large amount of time providing care for the ill or disabled person, or is having difficulty coping with the change in role. A means of coping, these avoidance behaviors serve to de-stimulate the child and insulate them from their feelings. By changing their role from “caregiver” to one of “member of the household,” there is no need for avoidance of what could be an intensely emotional situation. Though normal self-isolation behaviors may occur, they are less likely to be in response to feelings of stress related to the illness or disability.

Children are affected by illness in the household, just as it affects others in the home. When young people are put into the role of caregiver, there can develop a role-conflict and changing dynamic in the parent-child relationship that can manifest itself in both emotional and physical ways. Understanding the effects of this situation, the grief associated with the change in the home environment, and the stress response in the child can aid in making changes in the expectations of children in this setting, and help them cope and respond in a more positive and age-appropriate manner to this unique and challenging situation.

COMMUNITY OUTREACH & CHAPTER EVENTS

Strike Out 2022 ALS

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)

Unfortunately, the event on May 6 was cancelled due to bad weather. Visit our Events page on the Chapter Website for ticket exchange or refund options.

<https://bit.ly/DragonsStrikeOutUpdates>



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

5TH ANNUAL RACING MOWERS & KARTS

MOW DOWN

2 Brothers Race Way
9068 Limerick Rd
Chillicothe OH



Dry camping
available

Raffles

Food

Door Prizes

September 23rd

Practice @ 12n, Pit Party to follow. Sponsored by:
Live from The Kraken with Dozer Dave Podcast

September 24th - Race!

Gates open 8:00 a.m. Racing @ 1:00

Sponsored By:

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

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

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!

REMEMBERING

Cincinnati Area	Columbus Area	Dayton Area	Lima Area
	Daniel Maston 5-9-22	Mark Tyler 4-24-22	
	Clyde Fravel 5-4-22		
	Vonnetta Hart 4-25-22		
	David Kercksmar 4-23-22		
	Anthony Dibble 4-21-22		
	William Coverdale 4-16-22		
	Daniel Nichter 4-7-22		
	Wade Moening 4-6-22		
	Lynda Brininger 3-10-22		

FREE FOR PALS

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

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

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

<p>CINCINNATI CAREGIVER GROUP (current caregivers only)</p>	<p>No Group This Month</p>		<p>Yvonne Dressman, LSW</p>	<p>The Good Shepherd Lutheran Church 7701 Kenwood Rd Cincinnati, OH 45236</p>
<p>CENTRAL OHIO CAREGIVER GROUP (current caregivers only)</p>	<p>Monday June 20, 2022 1:00—2:30 pm</p>	<p>Open Discussion Dempsey Family Resource Center, Riverside Hospital In-Person Attendance Limited</p>	<p>Carleen Hubbell, BS, MA Melinda McGuire, MSW</p>	<p>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</p>
<p>CENTRAL OHIO SURVIVOR GROUP</p>	<p>No Group This Month</p>	<p>A social dinner to enjoy the company of those who have experienced a loss to ALS (Dinner on your own)</p>	<p>*Please RSVP to Carleen Hubbell chubbell@alsohio.org or 614-273-2572 ext. 110</p>	<p>T B D</p>
<p>CINCINNATI AREA SURVIVOR GROUP</p>	<p>No Group This Month</p>	<p>A social dinner to enjoy the company of those who have experienced a loss to ALS (Dinner on your own)</p>	<p>Host: Mary Naylor *Please RSVP to Mary Naylor at 513-891-1475</p>	<p>Slatts Pub 4858 Cooper Road Cincinnati, Ohio 45242 (Private Dining Room)</p>
<p>DAYTON AREA CAREGIVER GROUP</p>	<p>No Group This Month</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>DAYTON AREA SURVIVOR GROUP</p>	<p>Wednesday June 29, 2022 6:00-8:00 pm</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
Monday June 13, 2022 6:00 pm—8:00 pm Facilitator: Yvonne Dressman	CINCINNATI REGIONAL AREA Occupational Therapy 101 Connie Budda & Colton Sayers, UC Health OTs	In-Person Support Group The Good Shepherd Lutheran Church 7701 Kenwood Rd Cincinnati, OH 45236
Monday June 6, 2022 6:30 pm –8:30 pm Facilitator: Carleen Hubbell	COLUMBUS REGIONAL AREA Open Discussion—Attendance Limited (Virtual & In-Person Meetings Resume in July)	In-Person Support Group for June McConnell Heart Health Center 3773 Olentangy River Road Columbus, OH 43214
Monday June 13, 2022 6:30 PM – 8:30 PM Facilitator: Whitney Taverna	GREATER DAYTON REGIONAL AREA Open Discussion	In-Person Support Group Beavercreek Christian Church 3009 Shakertown Road Beavercreek, OH 45434
Tuesday June 7, 2022 1:00 pm—3:00 pm Facilitator: Whitney Taverna	MID-NORTHWEST OHIO REGIONAL AREA In-Home Care Support— A Panel Discussion Home Health, Private Duty Care, 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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