

Rod Callies Finds New Outlets for His Creativity Facing ALS

Rod Callies spent 33 years as an architect with his own business before he retired in 2012. Married to his high school sweetheart, Annette, for over 50 years, Rod – who had always been interested in art – decided to take some sculpture classes at the local community college.

Within a short period of time, not only had Rod completed almost a dozen outdoor sculptures, but his design, “Aspire,” won the city of Chesterfield’s public art contest in 2013. The completed piece is on display in Chesterfield Central Park near the amphitheater lake.

“Rod has always been a very creative individual,” Annette says.

The Callies Wildwood home is filled with Rod’s original art pieces: wooden bowls, lithographs, paintings, photographs, and of course his many unique sculptures.

In 2016, Rod noticed that his voice had become hoarse, but thought it was probably just a lingering sinus infection. When his tongue began twitching, he made an appointment with an ENT where it was revealed that one of his vocal cords was 90% paralyzed.

After being referred to a neurologist, and undergoing numerous tests, Rod was diagnosed with ALS in 2016, a year and a half after his first symptoms appeared.

Because the disease was bulbar onset, Rod lost his ability to speak, but has been able to continue working with his hands to create and build works of art.

His latest project is a series of books he is composing for his five young grandchildren to help them learn about his life and upbringing, as well as to record his memories growing up in and around the St. Louis area. He and Annette have organized family photos to include in each book, with



Annette and Rod Callies



“Aspire” sculpture in Chesterfield Central Park

Rod carefully using a customized lightbox to reproduce the images. He is doing his best to stay positive and stay focused on the project at hand.

“What’s important is how you respond to the disease,” Rod says. “Reach out to the people you love and let people love you.”



A sculpture on display at Callies Wildwood home

The books – six in all – are his primary focus at the moment, with sculpting taking a back seat.

“I like designing and building things with my hands, but now, because of ALS, I can’t do that anymore. My arms and hands are losing their strength,” Rod says.

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A letter from our Board Chair In It for Life

With the end of the year fast approaching, it's a good time to look back on 2018 as well as to thank all of you for all of the wonderful support you have provided. Through the end of September, the ALS Association – St. Louis Regional Chapter has served over 300 PALS. And, more PALS than ever before are receiving care from our ALS-affiliated clinics through our three St. Louis area medical facilities (the John A. Cochran VA Medical Center, Saint Louis University SLUCare and Washington University School of Medicine) and Cape Girardeau (St. Francis Medical Center). This is an important and welcome development as research indicates "people living with ALS can maintain independence longer and enjoy improved quality of life when given options for symptom management, assistive technology, adaptive equipment, education, care services, and emotional support" (ALS Association). Your continued support has helped make these ALS affiliated clinics a reality and helped improve the lives of those who are suffering.

This year we've also seen some wonderful events that brought thousands of people together for the purpose of raising awareness and funds to fight ALS. Both Walks were huge successes raising (together) almost \$600,000 which makes such a big difference in the Chapter's ability to support programs serving PALS as well as helping to fund cutting edge research. Looking out amongst all of the Walk teams participating in honor of or in memory of someone they love is tremendously inspiring. In fact, several of our top Walk teams are led by someone who is also fighting ALS. In the midst of all of the challenges of this disease, so many PALS are making a difference in lives of countless



others who are suffering. If you haven't experienced an ALS Walk before, please consider doing so in 2019 – you won't regret it!

Our "Swing for a Cure" golf tournament moved to a beautiful new venue this year and the annual "5Kimmswick Keep Your Eyes on the Pies" were two more ways (along with

many community sponsored events) that people participated in for a great cause. The "Ice Bucket Bash" helped close out what has been a tremendous year of support for which we are all grateful.

Another upcoming change will be with our own Board of Directors. At the end of this coming January, our current Vice Chair, Josh Rogers, will become the new Board Chair. Josh has ably served on the Board since 2012 and became involved after one of his best friends from high school died from ALS. He is a tremendously capable and dedicated individual who will serve the Board and PALS very well.

I have been most fortunate to be Board Chair since 2012. Our President & CEO, Maureen Barber Hill, the amazing Chapter staff, the Board of Directors, and hundreds of volunteers have made my job much easier. In addition, PALS and their families have all made this role one of the most rewarding things I have ever done – it has truly been my honor. I will continue working on the Board and look forward to seeing you at one of the many events that our Chapter hosts. We are all brought together by a terrible disease but in so many ways, ALS has made us all a family – a family that will fight this disease until there is a cure because we are – in the words of an ALS family member – "in it for life".

– Dave Van de Riet, Board Chair



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Please Welcome New Board & Staff

Anthony Mitchell **Board Member**

Anthony is currently an HR Director with Ascension, a faith-based healthcare organization and the largest non-profit health system in the U.S. Prior to joining Ascension, Anthony worked for SSM Health in St. Louis, MO, where he supported senior executives through major multi-state change projects, strategic initiatives and leadership development. Anthony's father passed in July 2017 from his battle with ALS. This along with his service to the health care community inspired his desire to join the board.

Michelle Reynolds Gray **Volunteer & Community Outreach Coordinator**

Michelle volunteered with patients, office support, and the Ice Bucket Bash for six years before joining full time

in April 2018. She supports volunteer recruitment, coordination and retention and serves as the point of contact for all volunteers and community engagement.

Jacqueline Kutz **Administrative Assistant**

Jackie aids all areas of the organization, including managing the Chapter's acknowledgement letter process, collecting daily donations, depositing donations into the online banking system and assisting with administrative projects.

Emily Ploch **Marketing & Communications Coordinator**

Emily supports the marketing and communication efforts of the Chapter through event development marketing and Chapter visibility and awareness. She writes and designs promotional materials, event materials and social media posts.

IN MEMORIAM

April 1, 2018 - October 31, 2018

In recognition of those who have recently lost their struggle with ALS, we remember their courage in living and keep their spirits alive in our memories. We will continue to fight in their honor.

Carl Aichholz
Kimberly Andrews
John Armstead
James Baker
Dennis Barbro
Bill Brendel
Cynthia Campbell
Larry Cline
Terry Crowe
Deborah Davis
Judy DeLuka
Jeanne Drummond
Carmen Gallo
Charles Gill
Kenneth Glanz
Ann Held
Janet Honesty
Cecil Horn
Mary Hutson
Wayne Jones
Robert Kemp
Sandra Kirby
Timothy Koenig
Julia Manton
Fredric McGruder

Robert Moore
Kathleen Palmer
Sharon Parsons
Jimmy Reece
Rosann Reed
John Rhoads
Dorothy Rogers
Michael Roy
Nancy Shields
Loren "Bud" Sowell
Harry Steingrubey
Dennis Stephens
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Betty Taylor
John Thyer
Christina Tinker
Willard Unnerstall
Keith Venneman
Sanford Wertheimer
Harvey White
Cyndee Wilcox
Kathleen Willcut
Mitchell York
Joe Zappa

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We regret any errors or omissions. Please contact the Chapter to request corrections or additions.

On our blog, ALS Connect:

Fighting in Memory of Grandma Ann



Molly with her grandmother, Ann Mangel



Celebrating grandma Ann at the St. Louis Walk to Defeat ALS®

By Molly Cruitt

Earlier this summer, I got married at the church I grew up in, three days after my grandmother's 78th birthday. My grandmother wasn't there.

It's been almost a full decade since my grandma lost her battle with ALS plus dementia, and it's easy to get lost thinking of all the things she's missed and the moments that will continue to happen without her present.

She wasn't there to see me walk down the aisle and marry my husband, who she never got the chance to meet. She wasn't present in that same church where she sat, afflicted with ALS and barely able to walk, at my confirmation – or where she bustled around, excited and full of life, at my first communion many years earlier. She wasn't there when we welcomed my nephew into the world. She won't meet my children someday, and she didn't know that I attended my dream school. I could dwell on won'ts and can'ts all day – but instead, as I celebrate a lot of exciting

new changes in my life that she can't and won't see, I'm fighting back.

ALS robbed my grandma of her life at the age of 69 – but along the way, it robbed her of so much more. It took away her voice, her legs, and her personality. This once feisty woman who had more energy in her sixties than I have ever had a day in my life, the one who would eat anything – her favorite foods being chocolate covered popcorn and Guinness anything – was swiftly taken away. In her stead was a small, scared woman who couldn't muster up the strength to eat and sometimes wasn't sure who I was.

It wasn't fair.

I don't know why ALS chose our family. I don't know why my grandma got so sick and passed away so quickly when she did – while I was applying for colleges, and while my sister was studying abroad. I can't change what happened and I can't bring my grandma back – but what I can do – what I will never stop doing – is use my voice to fight back every single day until there's a cure.

When people ask me why I volunteer with the ALS Association, it's not a difficult question to answer. I volunteer to give a voice to people whose voices have been violently ripped from them. I fight for a world where no one else has to watch her grandma disappear in front of her. I try my best to give to families who are suffering from ALS now the love and support my family received – whether that's helping a person with ALS tell his story so his daughters have something to hold on to for the rest of their lives, or documenting the moments of joy and struggle with my camera. I still have a voice, and I know my gifts well – so it's my joy, my responsibility, and my duty to use those gifts to make life a little easier for the voiceless and to fight unceasingly, today and every day, until we unlock a cure.

Molly Cruitt is a Walk to Defeat ALS® volunteer and member of the St. Louis Walk committee. She is a digital communications specialist in the St. Louis area and holds a Master of Arts from Saint Louis University and a Bachelor of Arts from the University of Notre Dame.



Visit our blog – ALS-connect.org!

You'll find stories, resources for caregivers, local event updates, research and advocacy news, as well as details on opportunities to engage with our Chapter and supporters. So connect with us and join the conversation!



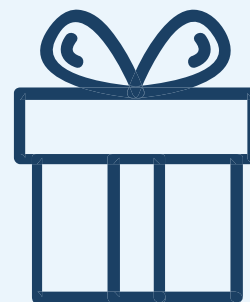
Jackson Man Recreates Masterpiece

Seventy-four-year-old James “Mike” Sciortino has been artistically inclined for most of his life. And while he used to design greeting cards before he retired, he now channels his artistic talents in another direction—hand embossed and engraved designs on Plexiglas. Working from a small space in his Jackson, Missouri living room, Sciortino carefully crafts each piece he creates with extraordinary attention to detail.

Sciortino’s designs range from sports team logos to landscapes and florals, but his most intricate work has to be his etching of Leonardo da Vinci’s *The Last Supper*, pictured here. The work requires a steady hand, one which he fears will soon be affected by his ALS diagnosis. “I’ll keep doing this as long as I can,” he says. “I enjoy making them for friends and family and I always carry some around to give to people.”

Looking for the Perfect Holiday Gift?

Make a Tribute or Memorial



Holiday shopping. We all have those people. You know them, the special folks who have everything, don’t need anything and make everything about the holding shopping experience “joyful.”

There is a solution. Go outside the box (and the wrapping paper and ribbon) and consider making a tribute or memorial gift on a loved one’s behalf. When you honor someone with a donation, you support a family with ALS while bringing true holiday warmth to an honoree. Planning to make an end-of-year gift? Simply indicate in writing that you would like that gift to honor someone special. Now you’re crossing things off your list!

All honorees will be notified that a gift has been made on their behalf with a card from the ALS Association St. Louis Regional Chapter. Donors can request that gift acknowledgments be sent to them for personal delivery.

Want to keep giving this holiday season? Get your friends involved with a holiday Facebook fundraiser. It’s easy, fast and there are no fees when you donate through Facebook—every cent goes to the chapter.

To make a gift, visit www.alsa-stl.org or call our office at (314) 432-7257. For more information on Facebook fundraising, visit <http://bit.ly/FBFundraiserALSASTL>.

Thanks to our Project Day volunteers



Centene volunteers spend time helping a person with ALS and their family by doing some fall cleanup.

Thank you to all of our corporate volunteers who helped people and families with ALS throughout the year through project days:

- Austin Machine
- Associated Bank
- Swank Motion Pictures
- Ursuline Academy
- John Burroughs School
- Missouri Baptist University Cross Country team
- RubinBrown

Whether it was helping families at their homes or lending a hand in the office, the Chapter is grateful for you! Your time and energy means a lot to people with ALS in eastern Missouri and central and southern Illinois.

If you would like the support of a volunteer in your home, please contact Michelle Reynolds Gray at 314-432-7257.

ALS Advocates Make Their Voices Heard in D.C.



This past May, thousands of ALS advocates traveled to Capitol Hill in Washington D.C. to share their experiences and educate legislators on issues that the ALS Community are facing. This year, a record number of people with ALS and their families attended the conference and told their story, including the Calmes and Hamlin families from Illinois and the Ziegler family from Missouri. These families along with thousands of other ALS Advocates from Chapters across the country shared firsthand how ALS and the lack of effective treatments affect their day to day lives. Each of our advocates met with members of congress to discuss The Association's 2018 public policy priorities and to talk about life before and after their ALS diagnosis.

2018 ALS Public Policy Priorities

Your voice matters. Below is an update on our public policy priorities along with which local representatives are supporting each initiative. If you don't see your Representative or Senator listed, and they continue to be in Congress, please contact them on the behalf of the Chapter or visit www.alsa-stl.org to take action.

Waive the SSDI Five-Month Waiting Period for People Living With ALS

Under current law, people disabled with ALS who qualify for Social Security Disability Insurance (SSDI) must wait five months before receiving benefits and Medicare. Every patient must wait regardless of the level of disability or how fast the Social Security Administration (SSA) approves the claim. The ALS Disability Insurance Access Act (H.R. 1171/S. 379) would eliminate the five-month waiting period for people with ALS so they can receive disability benefits and Medicare as soon as their application is approved by SSA. You can send a customizable letter to your members of Congress encouraging them to co-sponsor this important piece of

legislation, or thanking them for already doing so. As of early October 2018, Representative William Lacy Clay (MO), Representative Blaine Luetkemeyer (MO) and Representative Rodney Davis (IL) are the only supporters of this Act.



Save the Date for the 2019 Advocacy Conference



The 2019 National ALS Advocacy Conference will be held June 9 – June 11, 2019. The conference will take place at the J.W. Marriott Hotel in Washington, D.C. A web page with more information will be available in early 2019.

Sign up to be an advocate for ALS at www.alsa.org/advocacy You'll receive up-to-date alerts and support the Advocacy efforts of the Chapter.

Tiglutik –Thickened Liquid Riluzole – Receives FDA Approval to Treat ALS

Tiglutik™, the first and only thickened liquid form of riluzole, was approved by the FDA for the treatment of ALS. This formulation contrasts with the oral pill form of riluzole that has been on the market for ALS for more than 20 years.

This thickened liquid form of riluzole should help individuals with swallowing difficulties. Approximately 80 percent of people with ALS develop difficulty swallowing because of gradual weakness and paralysis in the muscles of the face and throat, called bulbar muscles.

In ALS, muscle weakness in the face and throat can lead to swallowing issues called dysphagia, along with problems with chewing, salivation, talking, and drinking. This often results in unwanted weight loss, issues taking oral medications, and in some cases, choking and aspiration, which is when food or liquid go down the wrong tube and into the lungs.

To counteract difficulties swallowing, many people with ALS end up crushing their pills. When medication is not taken as prescribed, its effect may decrease. Tiglutik provides an alternative as a thickened liquid, which can be administered orally twice-daily via a syringe. Its most common



side effects are in line with established side effects observed in oral riluzole.

“This approval marks an important step forward in the treatment of ALS. The ALS Association would like to thank the FDA and ITF Pharma for working together to bring this important new formulation of riluzole to the ALS community,” said Calaneet Balas, president and CEO for The ALS Association.

“ITF is committed to supporting the ALS community and to helping people living with ALS find affordable access to Tiglutik. Therefore, we have partnered with a specialty pharmacy to create a simple and straightforward product support program that will help patients

receive Tiglutik quickly and with ease. This reflects our underlying mission to provide valuable therapeutic options and support programs that make a positive difference in the lives of both patients and healthcare providers,” said Denny Willson, chief executive officer of ITF Pharma.

How riluzole impacts disease at a cellular level is not fully understood. Neurons signal to each other via chemicals in the brain, called neurotransmitters. One type of neurotransmitter is called glutamate, which gives out an excitatory signal.

Sometimes, glutamate does not get fully cleared from the space between neurons, called the synapse, leading to overstimulation or excitation to the connecting neuron. This over excitation can be harmful to neurons. Clinical studies have shown that riluzole modulates glutamate signaling.

ITF Pharma stated that Tiglutik will be commercially available mid-October 2018. The Association will keep the community updated as more information is available.

For more information about Tiglutik, including its side effects and safety information, visit <https://www.TIGLUTIK.com/>.

National ALS Registry

The National ALS Registry is continuing to take steps to further enhance the Registry for patients and researchers. Created in 2008, The National ALS Registry is the single largest ALS research project created designed to:

- Identify risk factors of ALS
- Connect patients with clinical trials
- Fund ALS Research
- Define disease statistics

In early 2017, the ALS Biorepository section of the ALS Registry is expected to launch and will be innovative in several ways:

- Trained phlebotomists will travel to donor homes to collect samples at no cost to the donor
- The de-identified samples can be paired with completed risk survey data
- Researchers will be able to collect a sample as-is or a sample that is paired with risk factor data

A biorepository is a national bank of biological samples like blood or tissue. The availability of additional specimens of people with ALS will further expand research on the genetics,



potential biomarkers and etiology for ALS. The samples that can be collected will include both a bio specimen component involved in the collection of blood, urine, hair and fingernail clipping samples collected prior to death, and a postmortem component involving the donation of brain; spinal cord; cerebral spinal fluid; and pieces of muscle and skin.

To enroll, call 800-232-4636 or visit www.cdc.gov/als.

Chapter Walks Raise



St. Louis | Forest Park, June 23
Presented by Dowd Bennett, LLC

More than 4,500 individuals and 154 teams joined us on a sunny day in Forest Park to walk in honor, memory and support of their loved ones. As of October 31st, the St. Louis Walk has raised \$420,829, which is 97.9% of our \$430,000 Walk goal.

Thank you to our Presenting Sponsor Dowd Bennett, LLP, and sponsors Raymond James & Associates, Inc., Ameren Missouri, Compassionate Nursing Services, Numotion, Inc., Permobil, Express Scripts Inc, Southern Bus & Mobility, The Family and Friends of Ray Van de Riet, Sr., United Access, LLC, Alliance Rehab and Medical Equipment, Missouri Foundation for Health, Quantum and Fresh Alliance LLC and to the official media sponsors of the Walk KPLR 11 and Fox2.



More Than \$584,000



Springfield | Southwind Park, June 16
Presented by The Jane and Mark Calmes Family

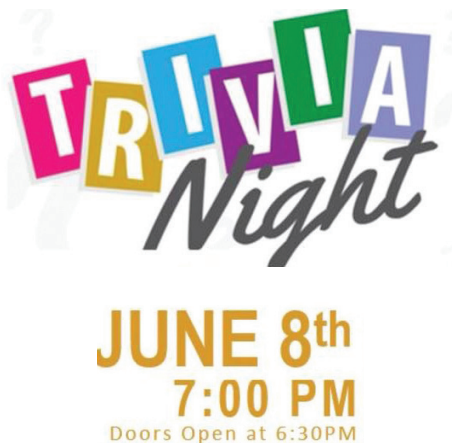
We had an incredible Springfield Walk to Defeat ALS® this year at Southwind Park with over 500 participants in attendance – a true testament of dedication, given the extreme weather conditions. As of October 31st, we have raised \$163,640, 93.5% of our \$175,000 goal, to support those fighting ALS.

Thank you to all the Walkers, teams, and the following sponsors for their support: the Jane and Mark Calmes Family, Graybar Electric, Brandt Consolidated Inc., Ameren Illinois, Personal Mobility, Warren-Boynton State Bank, WICS/WSRP, Culligan, Papa John's, Panera Bread, Ruler Foods and Casey's General Stores. A special thank you to John Spalding of 104.5 WFMB for being this year's Walk Emcee. Thanks to our media sponsors ABC 20 and WRSP Fox.



You Are the Key to Unlocking ALS

The keys our Walkers wore around their necks represent our commitment to unlocking the barriers to effective and compassionate care... to unlocking the physical constraints which threaten patients' everyday existence... and to unlocking the medical mysteries which will someday lead us to a cure. The lanyards we wear represent our diverse connections to ALS and this Walk. Each lanyard represents a different connection to the cause: everyone who wore a gold lanyard is a person with ALS, a blue lanyard means you are Walking in honor of someone, red indicates that you are there to support the fight and the cause, and white means you have lost someone to ALS. Walkers were also given the opportunity to write a special message about the reason they Walk on a paper key and hang it up in our Unlock ALS tent. We hope everyone who took part in the Unlock ALS ceremony enjoyed being a part of our community and we will continue this tradition into the 2019 Walk and beyond. So remember the key to a cure for ALS starts with you.



Team Pattie's Posse held their first trivia night at St. Louis Parish Center in Nokomis, IL and raised over \$6,000! They had a 50/50 raffle, music, individual paddle trivia and card deck drawings between rounds along with a prize for the best team name/decorated table. They held various other wraparound events as well – 2nd annual Pyros for Pattie 4th of July sparkler show and a Dairy Queen fundraiser on October 15th, where 50% of the sales that day went to their team.

Thanks to Our Community Partners!

Thank you to our community partners who organize such creative and fun events to raise money to support people and families battling ALS, and to help fund the search for treatments and a cure. We would like to acknowledge the following events held April 2018 through September 2018.

Cape Trivia Night

VFW Post 3838 hosted a Trivia Night for ALS on April 24th and raised over \$300 for our Chapter. In addition to trivia, there were also snacks and a drawing for four St. Louis Cardinals tickets along with a voucher for an overnight stay the Drury Inn and Suites.

17th Annual Jim Schoemehl Run

The 17th Annual Jim Schoemehl 5K Run took place on May 5th at Webster Groves High School. The event had a Star Wars theme and was organized by the student marketing club DECA to benefit a local family fighting ALS and the Association. They made a generous donation of \$2,000 to the St. Louis Chapter.

1st Annual Strikeout ALS for Ronnie Trivia Night



The Schneider Family along with many family members, friends and supporters helped organize a SOLD OUT trivia night in honor of Ronnie Schneider, diagnosed with ALS in July 2017. On May 12th, over 500 people gathered at the Carpenters Regional Council to show their support. Prizes, 50/50 and raffle items along with beer and snacks were provided. Proceeds went to help Ronnie throughout his ALS journey and over \$8,000 was awarded to the St. Louis Chapter.

Kickin' for ALS

The Grind Fitness and Sports Performance, a training and exercise facility located in South County, held a charity kickball tournament on July 21st, with all proceeds going to the Chapter. The winners of the tournament received t-shirts and were also recognized on the wall at The Grind. Over \$800 was raised!

Southern Illinois Miners ALS Night

The Southern Illinois Miners ALS Awareness Night was held on Saturday, August 25th. This year the pre-game Walk went around the ball field and a patient family threw out the first pitch. Facts about ALS were read throughout the game along with a staffed ALS table for anyone wanting more information or to donate. Overall, the event brought in over \$500 in donations!

Benton American Legion/VFW ALS Ice Bucket Challenge



Communities in southern Illinois came together on August 4th in Benton, IL, at the American Legion Post 280/VFW Post 2671 to raise awareness and funds for those affected by ALS. Over 20 individuals volunteered to take the Ice Bucket Challenge by getting doused under a tractor full of ice water. Overall, their efforts raised over \$3,000 – all donated to the ALS Association St. Louis Regional Chapter.

Southern Illinois Golf Tournament for ALS



Andy Clarke has been a champion for people with ALS in southern Illinois for many years, hosting events to support the St. Louis Regional Chapter's caregiver relief program in the area. This year, Clarke held a golf tournament on August 5th in Mounds, IL, at Egyptian Country Club. In addition to the golf tournament, \$2,300 was raised through a Facebook fundraiser. In total, \$7,800 was donated to help provide caregiver relief in southern Illinois!

Italian Open

The Italian Open has contributed approximately \$4 million to numerous primarily St. Louis-based children's charities since the initial Italian Open in 1974. Today, 30 to 40 local charities benefit from their event and the Italian Open distributes approximately \$150,000 annually. The Chapter has been one of the beneficiaries for the last several years. This year's dinner auction and golf tournament attracted 220 golfers, with the Chapter receiving over \$6,000 from the event.

GloRun 5K and 10K



All Community Events and Missouri Runs chose our Chapter to be the beneficiary for the GloRun 5K and 10K St. Louis in Forest Park on Friday, August 18th with \$3,200 donated to our Chapter. Participants wore glow-in-the-dark clothing and light-up necklaces and bracelets while running through glow tunnels and various other glowing structures.

Pullin' for ALS

Pullin' for ALS is always a fun-filled weekend at Edgar County Fair Grounds in Paris, IL, and this year was no different. The car show and dirt drags were on Friday, August 17th and truck and tractor pulls were on Saturday, August 18th. All proceeds were donated to the St. Louis Regional Chapter – 50% to fund research and 50% to patient and family services.

Mark Twain Two-Day Open Bass Tournament

For the second year in a row, the two-day Mark Twain Classic Bass Tournament took place on Saturday, September 15th and Sunday, September 16th at Mark Twain Lake. The event was hosted by The Hitching Post, 154 Marine and the Mark Twain Lake Chamber of Commerce, with a percentage of the proceeds going to the St. Louis Regional Chapter.

Interested in hosting your own community partner event? Visit www.alsa-stl.org and get started!



4th Annual Ice Bucket Bash

The ALS Association St. Louis Regional Chapter hosted the fourth annual Ice Bucket Bash November 16th at the Four Seasons, raising over \$478,000 to help people and families fighting ALS in eastern Missouri and central and southern Illinois.

Five local celebrities took the Ice Bucket Challenge live on stage to help us raise funds to fight ALS, including St. Louis Cardinals manager Mike Shildt; VP of Global Human Resources for World Wide Technology Ann Marr; President and CEO of So Hospitality Group Munsok So; on-air personality at KEZK Trish Gazall; and St. Louis Blues former defenseman Chris Pronger.

Joe and Kim Koenig served as honorary chairs for this year's event. Emcee for the evening's festivities was Y98 radio morning show personality Paul Cook, and auctioneer Graham Crow returned to help the crowd support their favorite celebs.

Ann Marr was crowned this year's "Ice Bucket Queen" for raising the most money from the crowd during the program and set the record for most money raised by a celebrity during the dunk.

A special thank you goes out to everyone who supported this event, especially our presenting sponsors, World Wide Technology and The Steward Family Foundation. Thanks to our sponsors Centene Charitable Foundation, Edward Jones, Emerson, Keeley Companies, Kim and Joe Koenig, Washington University in St. Louis, Graybar, Cardinals, Villa Lighting, Contemporary Productions, Switch, Maritz, Enterprise Holdings Foundation, Mercy, PNC Bank, Lou Fusz, Ameren, Bryan Cave Leighton Paisner, RubinBrown, Stinson Leonard Street, Crane Agency, Alliance Rehab, St. Louis Aquarium, Fox 2, KPLR 11, Evtiv and Inkwell.

8th Annual Kimmswick 5k

In Memory of Nancy Ratliff & Everyone With ALS



On Saturday, August 18th in downtown Kimmswick, MO, over 450 runners and walkers participated in this year's event. We raised over \$30,000, going over our goal! Guests enjoyed beer from Urban Chestnut, face painting and balloon animals from the Knights of Columbus District 44 Clown Club, photos and autographs from Olympic Triathlete Sarah Haskins and a free lunch from the Blue Owl Restaurant and Bakery.

A special thank you to our presenting sponsor, Blue Owl Restaurant and Bakery, and the Ratliff family. Thank you to our sponsors Ariix and J. Colin Leach, Home Service Oil, First Baptist Church of Arnold, The Material Works, United Access, Redfin, Burgess Orthodontics, Precision Dental Care, Vogel Heating and Cooling, Town of Kimmswick, Bradley Chiropractic LLC, Imperial Fruit Market, Urban Chestnut, Betsy N. Co. Creative and Inkwell.



Swing for a Cure Golf Tournament

Through a little rain and a lot of shine we had a great day raising funds and awareness for The ALS Association St. Louis Regional Chapter. Golfers enjoyed playing at the prestigious Sunset Country Club followed by a dinner and auction. We raised over \$80,000 with a sold out course of 144 golfers at this year's event.

Thank you to our sponsors Permobil, The Friends and Family in Memory of Wayne Barber, Sr., Aero Charter, Inc., Alliance Rehab and Medical Services, Graybar, GFI Digital, Barber Murphy Group Inc., Heffernan Insurance Brokers, RN Services of St. Louis Home Health LLC, Wine-Tapas and St. Louis Trust Company, along with our flag and hole sponsors.

UPCOMING EVENTS

Walk to Defeat ALS®

St. Louis | June 22, 2019
Springfield, IL | June 15, 2019

Kimmswick 5k

Saturday, August 10, 2019
Blue Owl Restaurant & Bakery

Swing for a Cure Golf Tournament

Monday, August 19, 2019
Sunset Hills Country Club


Ice Bucket Bash

November 2019

Stay in touch!

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OUR MISSION:

To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

Proud member of

United Way
of Greater St. Louis



ALS

ASSOCIATION

St. Louis Regional Chapter

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Chapter Director of Programs Tara Klucker and healthcare professionals from the ALS clinic at the VA St. Louis Healthcare System, John Cochran Division, delivered a presentation at the 8th Annual Paralyzed Veterans of America Healthcare Summit in Dallas, Texas this August. They spoke to conference attendees about the importance of a building a multidisciplinary healthcare team for optimal care of individuals with ALS. The St. Louis Regional Chapter is proud of the recently formed partnership with the VA to help treat veterans, who are twice as likely as the general public to be diagnosed with ALS.

From left to right, front row, Anndee Glick, Heather Van Meter, back row, Kim Von der Haar, Tara Klucker.