



St. Louis Regional Chapter

THE UPDATE

Bringing you the latest news on fighting Lou Gehrig's Disease in eastern Missouri and central & southern Illinois

Fall/Winter 2017

www.alsa-stl.org

First new drug approved for ALS in two decades

There is new hope in the ALS community - the FDA recently approved the first new drug in 22 years for the treatment of ALS. Radicava is described as a free radical scavenger that targets free radical damage to nerve cells. Free radicals occur naturally in the body as by-products of cell function, but when free radicals are too high it can cause cell damage called oxidative stress. Radicava helps get rid of excess free radicals and relieve the effects of oxidative stress. While this won't stop the disease, it could potentially help preserve function longer, enabling those with ALS to stay active and continue to do things they enjoy, especially those in the early stages of the disease.

Since the drug became available in the US in August, there are currently people receiving the treatment in all areas of our Chapter's service area in Missouri and Illinois, including Cape Girardeau, MO, St. Louis, MO and Hillsboro, IL. We are excited to be able to support people who would like to receive the drug, especially with the many challenges that come with this treatment. Mary Riggs, Director of Professional Services, says, "As exciting as a time this is for the ALS Community, it is also a very confusing time. Restrictions on the release of the drug through the Insurance Industry has made it not available to every patient. We are working with the local doctors, infusion centers and MT Pharma to accelerate the delivery of Radicava to those that qualify. We are also working hard to help those that don't qualify understand why and support them in every way possible." There are some challenges to receiving the treatment - one of which is finding an infusion site to receive the treatment and getting transportation to and from the site. To help with these challenges, MT Pharma America has set up a program called Searchlight Support to help people who have been prescribed Radicava access



Photo on left: Craig Farris, RN, CRNI, Home Parenteral Services of SEMO, administers a Radicava treatment to Shirley Brooks. Photo on right: Jason Krueger discusses Radicava with a clinical educator.



the medicine and help people find resources in their area. You can contact Searchlight Support by phone at 1-844-SRCHLGT (1-844-772-4548) or at <http://www.searchlight.radicava.com/hcp>.

We haven't yet seen what this drug holds in store for people living with ALS. Dr. Robert Bucelli, assistant professor of neurology at Washington University School of Medicine, describes the feeling best when he says, "We are cautiously optimistic. We don't think it is a home run, but we are hopeful." The fast approval and availability of Radicava also brings hope for other drugs currently in clinical trials. Currently, there are many promising drugs in late-stage clinical trials around the world. Someday, if these drugs are shown to be effective, they could be combined into a drug cocktail that could

greatly extend someone's life with ALS. For more information on research and current clinical trials, visit <http://alsa.org/research>.

For more information on Radicava:
<http://radicava.com> or
alsa-stl.org

For help with resources in your area:
www.searchlight.radicava.com
or call 1-844-772-4548

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A letter from our President & CEO

Your Support has Made the Difference

With the end of 2017 quickly approaching, we look back on the progress we have made this year and the many things we are thankful for. ALS gene discovery has exploded and is on the rise, and in just the past eighteen months there have been twenty-nine new genes discovered; all targets for new therapies. We have



Radicava, the first new drug on the market in twenty-two years currently treating patients, which will potentially slow the symptoms of ALS, and four new drugs currently in clinical trials (phases II and III).

It has been three years since the viral fundraising phenomenon known as the Ice Bucket Challenge helped us raise millions of dollars for our TREAT ALS research program. We are now starting to see the results of our investments with new extensive developments in ALS research that will make an impact on people with ALS and their caregivers. In the last year we have seen new findings and advancements in genetic and stem cell research. We have seen a surge of progress in technology and advances in antisense therapy for the two most common genes thought to cause ALS. The new development of an imaging marker for TDP 43, a protein formula found in most cases of ALS, has been initiated and led by Timothy Miller, MD, PhD, from Washington University. Each of these new innovations lead us closer to more effective treatments, discovering a cure, and most importantly gives us a new sense of hope.

This year's success would not be possible without the contributions from our community partners and stakeholders. This support has allowed us to provide the

best programs and services for those affected by ALS and to make a positive impact on people with ALS and their families. Your donations have allowed us to double the number of clinics working in conjunction with our chapter's case managers. Our new clinics are located at Washington University School of Medicine,

Neuromuscular Clinic and the John Cochran VA Medical Center (VA). They join the longstanding clinics at Saint Louis University's ALS Certified Center and St. Frances Medical Center in Cape Girardeau. Our case managers now provide coordinated services within the clinic sites with immediate follow-up possible with the clinics' multi-disciplinary team professionals. Of course none of this would be possible without the generosity of our local community, who generously invest in helping us make a difference in the lives of those we serve. From participating in chapter fundraising events to providing generous contributions, we are thankful to have such a powerful support from members of our community.

With the incoming New Year, we will remain diligent in our support of innovative research, new treatments, and search for a cure. We will continue to share stories with you of the many heroes with ALS. With another year done and dusted, we greet 2018 with an abundant amount of hope for the future, striving to make an even bigger impact on those and their families affected by ALS. Thank you for joining our fight against ALS. Together we are making a difference.

Happy Holidays to you from all of us.

Maureen Hill



CONTACT THE CHAPTER

**The ALS Association
St. Louis Regional Chapter**
2258 Weldon Parkway
St. Louis, MO 63146

Satellite Office
107 Campanella Drive
Sikeston, MO 63801

P: 314-432-PALS (7257)
1-888-873-8539

F: 314-432-2991

E: info@alsastl.org

W: www.alsa-stl.org

ALS.STL.Region

@ALS_STLRegion

Your gift can provide so much to a family dealing with an ALS diagnosis:



Connection

\$25

covers the cost of an LCD writing tablet, which allows a person with ALS to communicate with those around them.



Peace of Mind

\$100

funds two counseling sessions for a child coping with the effects of having a parent or grandparent battling ALS.



Relief

\$250

provides 10 hours of in-home respite care to allow a family member caring for a person with ALS a break.

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.

IN MEMORIAM

April 1, 2017 – Sept. 30, 2017

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.

Michael Allen
Kathleen Argent
Joseph Argo
Angelique Atwater
Jane Calmes
William Cantrell
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Mark Donovan
Lewis Dotson
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Marcia Sutter
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Donald Yeargain

The Chapter Staff

Maureen Barber Hill
President & CEO
mhill@alsastl.org, ext. 5

Shanna Akley
*Executive Assistant and
Operations Administrator*
sackley@alsastl.org

Mary Riggs, MS, CRC, LPC
*Director of Programs & Services
for Patient Care, Clinic & Research*
mriggs@alsastl.org, ext. 1

Tara Klucker, MA, CRC, LPC
*Director of Programs
& Evaluation*
tklucker@alsastl.org, ext. 7

Lori Dobbs
Care Services Coordinator
ldobbs@alsastl.org, ext. 236

Heather Burns
Care Services Coordinator
hburns@alsastl.org, ext. 233

Tonia Short
Care Services Coordinator
tshort@alsastl.org, ext. 229

Melissa Miller
Volunteer & Outreach Coordinator
mmiller@alsastl.org, ext. 232

Katie McGovern
Director of Development
kmcgovern@alsastl.org, ext. 2

Sarah Henke
*Development &
Communications Coordinator*
shenke@alsastl.org, ext. 8

Natalie Pottebaum
Development Manager
npottebaum@alsastl.org, ext. 230

Andrea Flanigan
Development Coordinator
aflanigan@alsastl.org, ext. 231

Sandra Sullivan
*Director of Marketing
& Communications*
ssullivan@alsastl.org, ext. 3

Pat Regan
Database/Office Administrator
pregan@alsastl.org, ext. 4

Debbie Craft
Staff Accountant
dcraft@alsastl.org

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

Day in the Life Photos on Display at Illinois State Capitol



In May, the Illinois State Capitol in Springfield, Illinois was home for the "Day in the Life" photo series of Larry Tyler and his family. The photos made quite an impression and were successful in raising awareness about ALS and what families facing the disease endure. Pictured with the exhibit is photographer Sarah Howell of Sarah E Studios, who is the talented artist behind the compelling photos. A special thank you to Sue Davsko, one of our extraordinary Walk committee volunteers and team captain of Johnny's Walkers, who coordinated the display.

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 holiday shopping experience "joyful."

There is 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.

To make a gift, visit www.alsa-stl.org, or contact the ALS Association office via phone.

\$100,000 Gift Honors Memory of Son Who Battled ALS



Ron and Anne Henges recently made a generous \$100,000 gift to The ALS Association St. Louis Regional Chapter in loving memory of their son, Larry Henges.

"We will honor and remember our beloved son by supporting others like him who are suffering from ALS who need care and support from this organization. We will not stop until we stop ALS. We hope others join us and make this your fight too."

Top:
Neil Henges, Jessica Henges Fierro, and
Larry Henges

Right:
Ron and Anne Henges



From our new blog – ALS Connect:

Growing Up With a Parent Who Has ALS: What I Learned

By Kelsey Lester



Lisa, Jeff, and Kelsey Lester

Growing up my chores included: cleaning my room, doing the dishes, putting the laundry away, and suctioning my dad's throat cannula. The last chore isn't typical of most kids, but my growing up wasn't typical. My dad was diagnosed with Lou Gehrig's disease in October 1993. I was born in May of 1995, and my dad is still kickin' it, so my relationship with ALS has been longer than most. My childhood and teen years didn't only include household chores that were different, but also different life lessons.

So, here is what I learned growing up in an ALS household...

I learned about how fragile life is.

Some of the first memories I have as a kid are of me laying on the grass, staring up at the sky, and trying to understand the concepts of life, death, and why we are on Earth. While this isn't the typical worries of a kindergartner, these concepts are what I had to process through at a young age. I had to understand that life is a gift that needs to be cherished and shared with others. The idea that our time on Earth is fleeting and could change or end at any moment has been a focal point in how I choose to live my life. My sisters and I are all people who try to live each day to its fullest and achieve all that we can, which I know is a direct result of our understanding that life doesn't always go as planned.

I learned about tenacity.

Tenacity, perseverance, and confidence are the attributes I have seen in my dad as he has battled ALS. Seeing these traits in him while growing up has shaped how I view the struggle of life, and to what extent I let life get me down. Life can throw curve balls at us at times, but doesn't mean that we can't stand back up after we've been hit. My life isn't an easy walk, but I can stand tall knowing that nothing can happen where I can't choose to persevere. My dad used to joke when I would have to give my life quote for school activities that it would be, "build a bridge and get over it," which I did use for my high school

graduation speech. My dad's fight has shown me that each mountain has a valley, but that the trek back up the mountain is worth it. I know that life can be hard, but that in the grand scheme of things, our lives, even with ALS, are filled with blessings.

I learned what loving another person means.

Being in an ALS household doesn't end with my dad having ALS. Having a parent who has ALS, also means that I have a full-time caregiver as a parent. My mom has stood next to my dad through all the stages as his mobility decreased, and has taken care of him 24/7 for over twenty-two years. My parents are a testimony that love and marriage aren't only about the milestones you want to experience with another person, but also about the sacrifices you are willing to make for another person. My parents have sacrificed everything for each other and our family, which shows since they are still married in a society that has a divorce epidemic. My parents aren't perfect, but they have, through ALS, set a standard for what love is.

And most of all...

I learned to laugh.

My family is always laughing. I would say that my parents have more reason than most people to be angry at the world, and to live a life of negativity. Instead, my parents chose positivity. With each hard time that my family has gone through, we have been there to pick each other up, and enjoy our time together by making fun of each other and the world that we live in. While I would say the downside to this is my crude sense of humor, I know that the upside of being able to laugh anything off and truly enjoy the company of others. Nothing can stop the laughter of my family, not even ALS.

Kelsey Lester, a recent graduate of Missouri State University, served as a communications and marketing intern for our Chapter last summer, and was our Walk to Defeat ALS Facebook Live correspondent this past June. Since getting her bachelor's degree in May, Kelsey has moved to St. Louis, traveled to Africa, and is preparing to apply to law school.



Visit our new 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!

ALS Association & VA Partner for ALS Clinic at John Cochran Division

The VA St. Louis, John Cochran Division, in partnership with The ALS Association St. Louis Regional Chapter, is pleased to announce that in May 2017, it opened the doors to a multidisciplinary ALS clinic. It offers local veterans multidisciplinary clinical services, and the expertise of a team of staff who are dedicated to the care, understanding and treatment of ALS. Under the direction of Dr. Brian Sommerville, the clinic is held on a bi-monthly basis on the 1st and 3rd Fridays of each month. Dr. Sommerville has 10 years of specialized experience working with ALS patients. "A goal of ours since 2008, when ALS became a service connected disability through the VA, was to open an ALS specific clinic for our Veterans to be able to get all their needs met at one location. I am excited to be a part of the multidisciplinary team and to help grow this clinic. I see such

wonderful things happening each and every clinic day and see this as a real asset to all Veterans," said Tara Klucker, Director of Programs.

Interdisciplinary ALS care has been shown through research evidence to improve patient outcomes, including life expectancy and quality of life. The Veterans Administration has the ability to provide comprehensive interdisciplinary ALS care that includes not only essential disciplines but also VA-specific programs such as home based primary care and integrated hospice and palliative care services. It brings together neurologists, nurses, social workers, physical therapist and occupational therapists, speech therapists, respiratory therapists, and nutritionists, as well as others needed to develop a comprehensive coordinated treatment plan.



The John Cochran VA ALS Clinic Team

Interested in learning more? Contact Tara Klucker at TKlucker@alsastl.org or 314-432-7257, or Anndee Glick, ALS Nurse Coordinator at (314) 652-4100 ext. 51176.

Clinical Trial: ALS Association and ALS Finding a Cure® Supported Phase II RNS60 Trial is Now Enrolling



The clinical trial to test RNS60, a new compound for the treatment of ALS, which was supported in part from a \$1.0 million grant through the ALS ACT initiative funded by The ALS Association and ALS Finding A Cure®, is now actively enrolling. This randomized placebo-controlled phase II study is being run by the IRCCS Mario Negri Institute for Pharmacological Research in Milan and the ALS Center of the Maggiore University Hospital in Novara, Italy. We are happy to report that the first patient was dosed in mid-July 2017.

The study is carried out in collaboration with the University Hospital AOU

Maggiore della Carità, Novara, Italy and involves 20 Italian ALS centers along with the Massachusetts General Hospital in Boston. The trial is led by neurologists Dr. Ettore Beghi, at IRCCS Mario Negri Institute for Pharmacological Research in Milan; and Dr. Letizia Mazzini at the University Hospital of Novara in Novara, Italy; and Dr. Sabrina Paganoni, at Massachusetts General Hospital in Boston.

The phase II trial will test the impact of RNS60 on selected pharmacodynamic and clinical markers in 142 ALS patients concurrently treated with riluzole and followed for 12 months. RNS60 and placebo will be given intravenously on a weekly basis and by inhalation in the remaining days for a period of 6 months. Patients will be followed for 6 additional months to measure long-term clinical outcomes. The trial is designed to assess the effects of the drug on selected disease markers and to correlate the changes in these biological markers to changes in disease progression.

RNS60 is a novel compound that is active on the immune system and inflammation, two mechanisms implicated in ALS disease processes. The

drug protects the integrity of neural cells by specifically modifying inflammatory pathways.

RNS60 exerts a protective effect on motor neurons in ALS cell and animal models. For example, when treated with RNS60, the well characterized SOD1G93A mouse model demonstrated a delay in the progression of symptoms and prolonged survival.

"In a pilot trial of RNS60 in ALS patients done at the Massachusetts General Hospital, the drug was safe and well-tolerated," said Dr. Sabrina Paganoni, co-investigator for the study and physician at the Massachusetts General Hospital and Spaulding Rehabilitation Hospital in Boston, MA.

The RNS60 trial is also supported by the Get OUT Onlus Association and the Fondazione Banco Popolare, Novara. Revalesio Corporation in Tacoma, Wash. provides the active RNS60 treatment and placebo.

For more information, including the contact information for the Massachusetts General Hospital trial site, will be made available on clinicaltrials.gov and on the Northeast ALS (NEALS) Consortium site.

2017 ALS Public Policy Priorities Include Patient Care, Research

Your continued support is needed! 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, 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

August 2017, Representative Lacy Clay (MO) is the only supporter of this Act.

Support the Steve Gleason Enduring Voices Act

The Steve Gleason Act of 2015 eliminated patient fears of having communication taken away and also ensured that "effective use" of the devices included critical eye-gaze coverage. But the 2015 Act is set to expire. These changes must be made permanent. As of August 2017, Representative Blaine Luetkemeyer (MO), Representative Rodney Davis (IL) have signed on to make this permanent.

Preserve Access to Complex Rehab Technologies (CRT)

In 2016, The Association worked with Congress and coalition partners, such as MDA, to enact legislation to preserve access to power wheelchair accessories such as custom head support and seating systems, mounting hardware, adjustable leg rests, and specialty drive controls among other wheelchair accessories upon which people with ALS depend. The Centers for Medicare



and Medicaid Services (CMS) was scheduled to significantly reduce payments for these accessories; however, The ALS Association worked with partners to successfully lobby Congress to delay implementation of these cuts. In 2017, The Association will work to implement a permanent solution through the legislative or regulatory processes. As of August 2017, Representative Blaine Luetkemeyer (MO), Senator Roy Blunt (MO), Representative Rodney Davis (IL), Representative Mike Bost (IL) and Senator Tammy Duckworth (IL) are supporting this issue.

ALS Advocates Make Their Voices Heard in D.C.



Every May, thousands of ALS advocates travel to Washington DC to meet on Capitol Hill 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, Robertson, and Hamlin families from Illinois along with the Ziegler family from Missouri. These families along with thousands of other ALS Advocates from Chapters across the country shared first-hand how ALS and the lack of effective treatments affect their day to day lives. Each family was able to meet with members of Congress and their staff to talk about life before and after their diagnosis along with the Association's public policy priorities of 2017.

New Comprehensive ALS Review Published

In the July 13, 2017 issue of *The New England Journal of Medicine*, leaders in the ALS field, Drs. Robert Brown of University of Massachusetts Medical School and Dr. Ammar Al-Chalabi of King's College London, came together to write a comprehensive ALS review. The article is far-reaching in that it covers topics from ALS epidemiology, genetics, pathology, identified disease pathways and potential ALS therapies. Familial (inherited) ALS and sporadic (not inherited) ALS are covered.

Both authors Drs. Brown and Al-Chalabi are past recipients of our prestigious Sheila Essey Award. The accomplishments of Dr. Brown are numerous, as he is well known for playing a central role in the discovery of many ALS genes, including the first gene identified, SOD1. Dr. Al-Chalabi is a genetics expert, who has also helped identify multiple ALS genes and has made significant contributions to understanding disease staging as Director of King's MND Care and Research Center.

Posted with permission from The New England Journal of Medicine.

Citation: Brown RH, Al-Chalabi A. N Engl J Med. 2017 Jul 13;377(2):162-172. doi: 10.1056/NEJMra1603471. Review.

Chapter walks raise



St. Louis | Forest Park, June 25

As of October 31st the St. Louis Walk has raised \$404,00 which is 84% of our \$477,000 Walk goal.

Thank you to our 2017 Walk Sponsors!

Presented By: Dowd Bennett, LLP

Sponsored By: Permobil, Raymond James & Associates, Inc., Ameren, Compassionate Nursing Services, Numotion, Inc., Express Scripts Inc, Southern Bus & Mobility, Alliance Rehab & Medical Equipment, Bethesda, Missouri Foundation for Health, Prism Medical Ltd., RespirTech, Travelers Insurance, UPS, Anchor Health Care, APP2Speak and Fresh Alliance LLC

Media Sponsor: FOX2/KPLR11 in St. Louis



more than \$608,000

Springfield | Southwind Park, June 11

The Springfield Walk to Defeat ALS at Southwind Park had a remarkable year! Over 700 participants came together to raise over \$205,000 to support people fighting ALS. Thank you to all the teams, walkers and the following sponsors for their support: the Jane and Mark Calmes Family, Memorial Health System, Graybar Electric, Hickory Point Bank and Trust, Personal Mobility, Warren-Boynton State Bank, WICS/WSRP, Hy-Vee, and Papa John's.



Team Spotlight: Jane's Angels



Jane's Angels, led by Team Captain Mark Calmes, has had their most successful year to date, surpassing their \$100,000 goal set for 2017. Since 2010, the team has raised over \$500,000, and we cannot thank Mark enough for his support and hard work not only to the Springfield Walk and our Chapter, but for his commitment to finding a cure for ALS at the national level. Thank you to the Mark Calmes Family and Jane's Angels for their continued dedication!

Our sympathies go out to Mark and his family on the loss of their beloved Jane, who lost her battle with ALS this summer.

Walk Wraparound Events: Putting the "fun" in Fundraising!

A great way to raise money for your Walk team is to host a wraparound event. It takes a little work, but the reward is huge. You don't need to do something that large; you can have a yard sale in your backyard or a bake sale at work. Hosting an event is a great way to get the community involved, increase your fundraising efforts and spread awareness about ALS. Here are a couple of examples of Walk wraparound events that were incredibly successful!

TEAM ARMY

Rob Robertson raised over \$1,900 with his gun raffle fundraiser at The Range St. Louis West. Rob, pictured right, raffled two guns from his own collection, got donations for the runner up prizes and had food and drinks donated for the event. Rob had people all over the community supporting him -- they hosted lemonade stands to raise money for Team Army and Rob even received a \$1,000 donation from Cardinal Buick GMC.



TEAM NAUGLE

Team Naugle, lead by Martinez "Marty" Naugle, has been active with the Springfield Walk since 2013, after Marty was diagnosed with ALS. This year was by far their best year yet -- they raised \$9,566 from a poker run and a handful of other various fundraisers. They placed 3rd in fundraising out of the over 30 teams that participated! Way to go Marty and Team Naugle!



3rd Annual Ice Bucket Bash Raises Over \$300,000

The ALS Association St. Louis Regional Chapter hosted the third annual Ice Bucket Bash November 17th at the Coronado and raised over \$300,000 to help people and families fighting ALS in eastern Missouri and central and southern Illinois.

Five local celebrities, Television Analyst and former St. Louis Blues player Bernie Federko; Broadcast and Web Meteorologist Cindy Preszler; President of Baseball Operations for the St. Louis Cardinals John Mozeliak; Fox2/KPLR11 Reporter and Anchor Dan Gray, and Rusty Keeley, CEO of the Keeley Companies; all took the Ice Bucket Challenge live on stage to help us raise funds to fight ALS.

Emcee for the evening's festivities was Y98 radio morning show personality Courtney Landrum, and Auctioneer Graham Crow helped the crowd to support their favorite celebs.

Rusty Keeley took home the evening's honor of "Ice Bucket King," awarded for raising the most money from the crowd during the program.

A special thank you goes out to everyone who supported this event, especially our presenting sponsors, WorldWideTechnology & The Steward Family Foundation. Additional sponsors included The Fox Family Foundation, Centene Charitable Foundation, the Keeley Companies, the St. Louis Cardinals, Washington University in St. Louis, Stinson Leonard Street, Edward Jones, RubinBrown, Alliance Rehab, Graybar, Evtiv, CAM Print, and our media sponsor, Fox 2/KPLR 11.



Annual Golf Tournament

On August 25, at the Norman K. Probst Golf Course in Forest Park, over 150 golfers took part in our Annual Golf Tournament. This year's tournament was renamed Swing For a Cure to focus on the excitement surrounding research updates in the ALS community. We had wonderful weather and a course full of generous golfers that helped raise over \$82,000. Golfers enjoyed 18 holes of golf, drinks from Mastermind Vodka, Urban Chestnut Brewery, Anheuser-Busch and steak sliders from Ruth's Chris Steakhouse. After their round back at the club house we had music from Joe Fry, a themed buffet including an ice cream sundae bar from Ted Drew's and emcee Sherry Farmer on air personality at CBS St. Louis was on hand. Our sincere appreciation and thank you to our sponsors, participants, golf committee and the event day volunteers for their involvement, generosity and support at this year's Tournament we could not accomplish this without their dedication and support.

Thank you to our 2017 Golf Sponsors:

Associated Bank, The Family & Friends of Wayne Barber, Sr., Alliance Rehab, Permobil, AeroCharter, United Access, BarberMurphy Group, Graybar, Mark & Kathy Slocomb and Numotion.

7th Annual Kimmswick 5K *In Memory of Nancy Ratliff & everyone with ALS*

It was a beautiful day on August 19th for the 7th Annual Kimmswick 5K – over 400 runners, walkers and their families came out to downtown Kimmswick for the race and helped raise over \$24,000!

We would like to thank all of the volunteers and sponsors that helped make this event a HUGE success! A special thank you to the Blue Owl Restaurant and Bakery, the Ratliff family, Ariix and J. Colin Leach, Home Service Oil, First Baptist Church of Arnold, Burgess Orthodontics, Precision Dental Care, The Material Works, Town of Kimmswick, Midwest BankCentre, Edward Jones, Vogel Heating and Cooling, Urban Chestnut, Perennial Artisan Beer, Green Light Campaigns, Ron Harder at Rock Community Fire Department, Kimmswick Police, Corporal Allen Flannery at Missouri State Highway Patrol, Knights of Columbus District 33 Clown Club, and Sarah Haskins.

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 2017 through September 2017.

Phi Delta Theta Trivia Night

Phi Delta Theta fraternity and VFW Post 3838 hosted a Trivia Night for ALS on April 25th and raised over \$300. Everyone had a good time testing their knowledge – all for a good cause!

16th Annual Jim Schoemehl 5K Run



The 16th Annual Jim Schoemehl 5K Run took place on May 6th and was organized by Webster Groves High School students to benefit a local family fighting ALS and the Association. They made a generous donation of \$1,500 to the St. Louis Chapter.

Missouri State ALS Baseball Game

The Missouri State baseball team organized an ALS Awareness game in honor of Barb Paulsen to show support for fellow player Justin Paulsen. The team raised \$581!

American Airlines Ice Bucket Challenge



On their lunch break, American Airline employees were greeted by ALS Association Staff and Tee Tee Perez, fellow American Airlines employee and event organizer, on the tarmac with snacks, drinks and ice cold buckets of water – they took the ice bucket challenge to help raise money for the Association.

Southern Illinois Miners ALS Awareness Night



On August 18th, Abby Malloy and ALS Staff organized an ALS Awareness Night at Rent One Park. A walk was organized prior to the game along with a moment of silent and various ALS related activities throughout the 9 innings. The event brought in over \$3,500 in donations.

Pullin' for ALS



The 5th Annual Pullin' for ALS tractor pull took place in Paris, IL on August 18th and 19th. Organized by Lesley Mills and her brother Josh Elsberry in memory of their mom, Beckie Galbreath, the event raised over \$10,000 for ALS research and family services.

Cardinals Wives Grab Bag Fundraiser



The St. Louis Cardinals' Wives selected the ALS Association, along with St. Louis Crisis Nursery, to participate in their annual Grab Bag Fundraiser. We sold all 600 baseballs (autographed by all the Cardinal players) before the first pitch – a record we are told - and raised over \$10,000 for our Chapter! Also, patient Steve Ziegler and his family went on the field for the pre-game announcements prior to the game.

The Smile Shoppe



During ALS Awareness Month, the doctors, staff and patients at The Smile Shoppe in Highland, Illinois raised over \$530 for people with #ALS and their families! While The Smile Shoppe team regularly raises funds for charity, this particular cause is near and dear to their hearts -- dental assistant Krisi Schulte lost her husband, Brian, to the disease late last year.

Lemonade Stand



Gretchen Venghaus, Katelyn Irvin, Emily Gump and Paige Hammerschmidt sold lemonade this summer to raise funds for people fighting ALS in our community. These enterprising young ladies raised \$200 by asking people to "squeeze out Lou Gehrig's disease"! Thank you Gretchen, Katelyn, Emily and Paige for your help in supporting people with #ALS and their families!

Highland Middle School Fundraiser

Highland Middle School students raised nearly \$500. The kids at Highland have been fundraising for people with ALS for many years. We appreciate their support!

Interested in hosting a community partner event?

Visit www.alsa-stl.org and get started!

UPCOMING EVENTS

Walk to Defeat ALS®

Springfield, IL | June 16, 2018

St. Louis, MO | June 23, 2018

Kimmswick 5k

August 18, 2018

Blue Owl Restaurant & Bakery

Swing for a Cure Golf Tournament

August 20, 2017

New Location!

Sunset Hills Country Club

Ice Bucket Bash

November 2017

ALS

ASSOCIATION

St. Louis Regional Chapter

2258 Weldon Parkway

St. Louis, MO 63146

www.alsa-stl.org

314-432-7257

1-888-873-8539

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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.



Missouri Senator Jill Schupp, District 24 (pictured second from left) stopped by our Chapter offices to visit staff and volunteers and learn more about ALS and the issues facing families who are dealing with an ALS diagnosis. Thank you Senator, for your interest and pledge to help people with ALS in your district!