



St. Louis Regional Chapter

THE UPDATE

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

Spring 2018

www.alsa-stl.org

Cathy Bechtold's Family Embraces the Power of Laughter

Since her diagnosis of ALS in May of 2014, Cathy Bechtold has faced a lot of changes, but her family's encouragement and her sense of humor have remained constants in her life. Cathy's family - especially her three children and her sister - make up a strong support system that have kept her smiling and helped her to maintain her independence as she goes about daily life with the disease.

Cathy's daughter Kelly has made sure that Cathy stays mobile for as long as possible, getting a power chair and a van with hand controls for her mom, and helping overhaul Cathy's bathroom to make it wheelchair friendly. And, because Kelly's home is a one-story, mom and daughter actually switched houses to allow Cathy to remain at home and independent longer. Cathy says that Kelly gives her the "big, loud, push" that is sometimes necessary to make the changes in her lifestyle that an ALS diagnosis requires.

While her family makes sure that she is taken care of physically, they also provide the emotional support that helps contribute to Cathy's positive attitude. Her first grandchild was born when Cathy was going through the process of diagnosis. She describes him as her "little blessing" during that time and a welcome distraction from the devastation of learning she had ALS. Since then, Cathy has had three more grandchildren. "They are my joy. They make me laugh even when I don't feel like it," she says.

Cathy will be cutting the ribbon at the St. Louis Walk to Defeat ALS® this year, on June 23rd in Forest Park, and her family and friends will be at her side. Her team name, "Cathy's Favorites," originated because of a special family joke. "When my kids were growing up, they always used to ask me which one of them was my favorite. So whenever one



Cathy Bechtold and Team Cathy's Favorites at the 2017 Walk to Defeat ALS®

of them would do something nice for me, I would tease them and shout out that that one was my new favorite," Cathy laughs.

Cathy says that she gets told "you're amazing" and "you're such an inspiration" all the time. But she says the ability to cope is in everybody. "If that's inspirational, that's ok. There's nothing special about me. It's in all of us. It's in everybody to help someone." It's something that she's seen firsthand in her friends and family. Cathy says that she's constantly amazed by the many things that people do for



At the finish line in 2017

her to try and make her life easier. One friend recently purchased a pot with a built in strainer to help her make pasta, something she wouldn't be able to do otherwise. Cathy says not only is she very appreciative of all the efforts to support her, but that she loves seeing the smile on people's faces when they can help.

You can support Cathy and other people fighting ALS by participating and donating to the Walk to Defeat ALS®, WalktoDefeatALS.org

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A letter from our President & CEO

We have had the privilege of serving people with ALS and their families in eastern Missouri and central and southern Illinois for over thirty years. The cost of care for families fighting ALS is staggering, and we are committed to helping to alleviate some of the physical and financial strain while we search aggressively for treatments and a cure. Because of you - our dedicated supporters - we are able to provide programs and services, free of charge, to ease the burden of families battling ALS and help them live every day to the fullest. None of what we do would be possible without your support. Thanks to you we are making progress in this fight, but we still have far to go.

Our primary and continuing focus at The ALS Association St. Louis Regional Chapter is on increasing the quality of life for individuals facing an ALS diagnosis, and finding a cure. In 2018, we are taking steps to re-examine and measure the impact of our programs and services to ensure that every dollar we raise is making the greatest difference possible in the lives of people with ALS and their families. We want to find out where there is the greatest need, and how we can meet it. We are working to fund new and innovative technological solutions that will allow families to remain physically and emotionally healthy, together in their own homes, and to help them to live a life beyond ALS. We also know that in-home care continues to be a pressing concern for so many of our families living with ALS, and we are exploring ways to address this issue and offer some solutions.

These are weighty challenges, but as a community, I know we are up to the task. When we come together, we can make the impossible possible!



In just the past few months, researchers from collaborative initiatives funded by The ALS Association, with money raised through the ALS Ice Bucket Challenge, announced the discovery of a new ALS gene, KIF5A, which will help drive new discoveries and fuel the ALS treatment pipeline. This is the fifth new ALS gene discovered since 2014 through

research supported by The ALS Association and made possible by our donors. Over 25 ALS genes have been discovered, so far, but the rate of discovery has greatly accelerated since the Ice Bucket Challenge.

And just recently, we saw the launch of Project Revoice, which will give people with ALS the ability to communicate with their own voices, even after they can no longer speak. Project Revoice is powered by breakthrough voice cloning technology, developed by our Canadian software partner Lyrebird. With 2-3 hours of high-quality audio recordings to work with, this model can synthesize the essence of your voice and build a complete digital recreation of it.

These successes are a direct result of friends and mission champions, who so generously give of themselves in order to make lives of others better. I am continuously reminded of how giving and committed our supporters are. I see it at our fundraising and awareness events, on our corporate project days, and in the faces of our long-time volunteers. We will be asking for your help again this year as we work to generate an even greater impact on families and seek new breakthroughs in assistive technology and research.

Working together, we can achieve something amazing!

Maureen Hill



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When you make a donation to The ALS Association St. Louis Regional Chapter, you help us provide free programs and services for people with ALS and their loved ones, as well as fund the search for treatments and a cure.

IN MEMORIAM

Oct. 1, 2017 - March 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.

Lynne Brennan-Howk

Gary Kiefer

Tom Melvin

Deborah Nicks

Sandra Schulte

Jay Mareschal

Robert Zewiski

Thomas Troynell

Michael Murphy

Gladys Lehnhof

Audrey Rowland

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Rebecca Clifford

Diana Ortals

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Marilyn Cisler

Michael Brainerd

William Fry

Michael Galkowski

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Carmen Berkley

Charles Pohlman

Christine Schwantner

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

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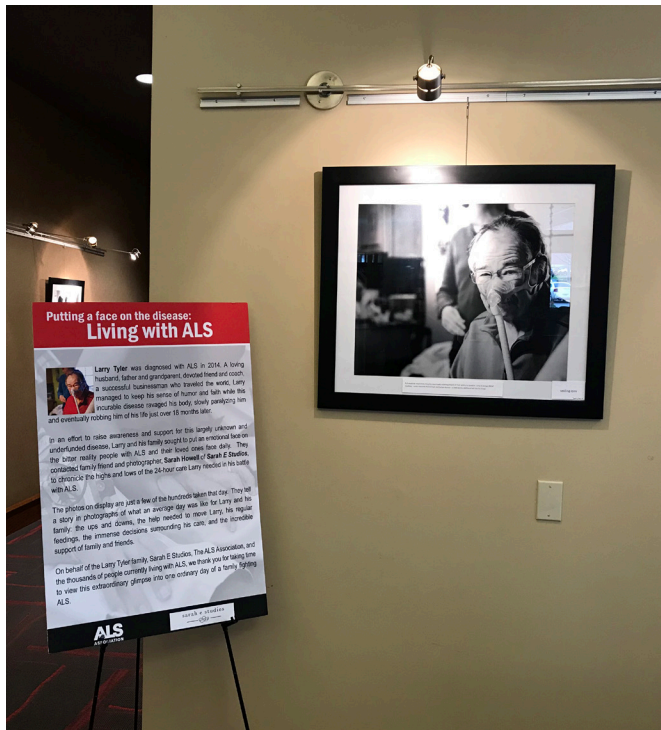
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Day in the Life on Display at the St. Louis Public Library

The Day in the Life display was on the move again! During the month of March, photo series found a new home at the Schlafly Branch of the St. Louis Public Library. The photos of Larry Tyler and his family - taken by the talented Sarah Howell of Sarah E. Studios - continue to raise awareness of ALS and what families fighting this disease experience every day.

Our Blog

ALS-Connect

Inform, Educate, Participate.

Visit our blog, [ALS-Connect.org](https://www.alsastl.org), to find stories, resources for caregivers, local event information, research and advocacy news, and more. Do you have an idea for a blog post? Send your suggestions to info@alsastl.org today and we might feature your idea in a future post!



On our blog, *ALS Connect*: Living with ALS: Keep Your World Large

By Julia Henderson-Kalb, OTD OTR/L and
Elissa Held Bradford, PT, PhD, NCS

What do you want to be able to do in a day? What activities are important to you? Everyone craves activity. It is part of our human experience. However, oftentimes when people are diagnosed with a disease like ALS, their world tends to shrink. They might isolate themselves, stay at home the majority of the time, and stop doing the things they love to do in exchange for activities that aren't very meaningful to them, like watching TV for hours on end. As part of the therapy team at Saint Louis University's ALS Certified Center of Excellence, one of our priorities is to help people diagnosed with ALS understand how to keep their world LARGE so that they can enjoy meaningful activity for as long as possible.

What causes the world to shrink for someone living with ALS? It might be physical. The loss of mobility due to muscle weakness, balance issues, or low endurance can make it more difficult to get from point A to point B. Getting into and out of a car or using public transportation can be a problem. Once you arrive at your destination, maneuvering around might be challenging for many reasons—if there is a great distance to cover, the terrain isn't smooth, or there isn't enough space to move comfortably, to name a few. Loss of fine motor coordination and gross motor coordination can make completing daily activities more complicated.

Other causes of isolation from the world might not be as physically obvious but are no less influential. People living with ALS often experience feelings of depression, loss of control, and loss of “sense of self” when they are having difficulty or no longer able to complete daily activities in the way they once did. A common example is no longer going out to eat with family and friends, despite enjoying and participating in this activity frequently previously. When searching out the reason for this change, it is often embarrassment related to challenges with eating such as dropping utensils or coughing a lot. Furthermore, the loss of ability to verbally communicate with others has been found to be linked to a decrease in quality of life.

So what can be done to overcome these barriers and keep your world LARGE for as long as possible? There are several strategies to be considered to stay engaged in meaningful activities.

1. Exercise/Physical Activity
2. Activity/Environmental Analysis
3. Equipment
4. Delegation
5. Focus on What Matters Most

*Read the entire post on our blog
www.ALS-Connect.org.*

Elissa Held Bradford, and Julia Henderson-Kalb are part of the multidisciplinary care team at the ALS Certified Center of Excellence at Saint Louis University Hospital.



Steve Ziegler and Lynn Hogan

Steve Ziegler honored with Hero Award

Congratulations to Steve Ziegler - ALS Advocate, Walk to Defeat Team Captain, FDA drug guidance development initiative participant, clinical research ambassador, Chapter spokesperson - who was honored in February with the Hero of Hope Award at the ALS Association's national conference. Steve, who has been living with ALS for the past three years, was recognized for his tireless commitment to battling the disease on every front. Steve is well known in the ALS community, and works diligently to help people understand the need for more support for people living with ALS and their families.

The Hero of Hope Award is the highest honor given by The Association, and recognizes and pays tribute to people living with or who have lived with ALS and who have made an “indelible impact on The ALS Association and the community at large.” Those honored with the award have inspired the ALS community as they have promoted awareness of Lou Gehrig's disease and have sought to improve the lives of people with ALS.

Thank you Steve, for all of the wonderful work you do for the ALS community!

2018 Legislative Priorities

LEGISLATIVE ASKS

1. Ensure at least \$10 million in appropriations for the ALS Registry at the Centers for Disease Control (CDC).
2. Ensure at least \$10 million in funding for the Department of Defense's (DOD) ALS Research Program.
3. Support increased funding for the National Institutes of Health (NIH) in FY2019, especially the National Institute of Neurological Disorders and Stroke (NINDS)
4. Pass the ALS Disability Insurance Access Act (S.379/H.R.1171) to waive the five-month waiting period for patients with ALS before receiving benefits under Social Security Disability Insurance

LEAD INITIATIVES

Secure Appropriations for Key ALS Research

1. National ALS Registry – Provide \$10 million appropriation to continue the National ALS Registry and Biorepository at the Centers for Disease Control and Prevention. The Registry collects data and directs a biorepository for people living with ALS and collaborates with the Centers for Medicare and Medicaid Services, the Veteran's Administration and the National Institutes of Health (NIH). It is a critical driver of the search to find treatments and a cure because it connects researchers conducting clinical trials with people living with ALS in addition to funding its own research.
2. Department of Defense – Provide a \$10 million appropriation to continue the ALS Research Program (ALSRP) at the Department of Defense (DOD). Research has repeatedly demonstrated that military veterans, regardless of branch or era of service, are approximately twice as likely to die from ALS than civilians. The ALS Research Program (ALSRP), funded as a part of the Congressional Directed Medical Research Program at DOD, provides competitive grants that are an essential component of efforts to identify treatments and a cure for ALS.
3. National Institutes of Health – Continue ALS Research at the National Institute for Neurological Disorders and Stroke and other Institutes at the National Institutes of Health (NIH). NIH spends approximately \$55 million for ALS research with National Institute of Neurological Disorders and Stroke (NINDS) making the largest investment and four other NIH Institutes contributing the balance. The ALS Association works with Research!America to advocate for appropriate funding so that NIH can maintain and increase this level of commitment to ALS research.

Waive the 5-Month Waiting Period for Social Security

1. The ALS Association was responsible for introduction of the ALS Disability Insurance Access Act (S.379/H.R.1171) in early 2017 to eliminate the five-month waiting period for Social Security Disability Insurance (SSDI) or Medicare. Under current law, people with ALS who qualify for Social Security Disability Insurance (SSDI) must wait five months before receiving SSDI and access to Medicare. The legislation, if enacted, would eliminate the five-month waiting period for people with ALS.



Access to Home Health Services

1. Achievable policy solutions are needed to improve access to home health services for people living with ALS. Federal government concerns about waste, fraud, and abuse of Medicare home health benefits for all seniors and misunderstandings about the scope of the benefit have significantly limited access for people living with ALS. In 2018, The ALS Association will continue to educate and advocate with the Administration and Congress on the home health needs of people with ALS as well as identify achievable ways to remove barriers through regulatory and legislative action.

PATIENT ADVOCACY

Represent People Living with ALS in the Health Care Reform Debate

The ALS Association continues to work with leading patient advocacy groups on legislation impacting people living with ALS as issues evolve. Examples include tax reform in 2017, specifically the fight to maintain the Orphan Drug Tax Credit and the Medical Expense Tax Deduction, but as Congress and the administration consider changes to the Medicare and Medicaid Program, the Association will closely monitor and work with other patient advocacy groups to examine emerging proposals to determine their impact on people with ALS and their families.

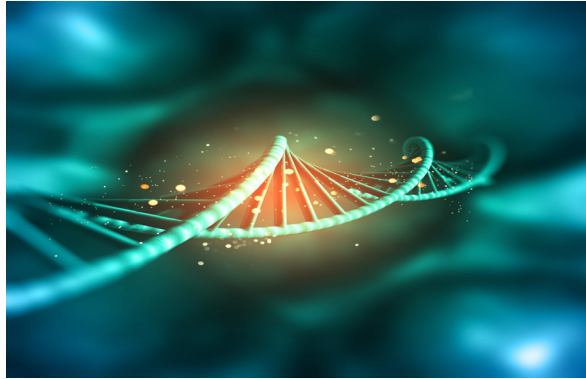
Raise your voice for people with ALS. Sign up to be an ALS Advocate today!
www.alsa-stl.org

Ice Bucket Dollars at Work: New ALS Gene KIF5A Discovered

Researchers from collaborative initiatives funded by The ALS Association, with money raised through the ALS Ice Bucket Challenge, announced the discovery of a new ALS gene, KIF5A, which will help drive new discoveries and fuel the ALS treatment pipeline.

Researchers from organizations Project MinE, Genomic Translation for ALS Care, Answer ALS, the Target ALS Postmortem Tissue Core, the New York Genome Center (NYGC) ALS Consortium, the CReATe Consortium, the National Institutes of Health (NIH), and others came together to collaborate and share detailed genetic and clinical information needed to make this important discovery. The Ice Bucket Challenge enabled The ALS Association to support the above unique collaborative initiatives in precision medicine to accelerate the discovery of new treatments for ALS.

KIF5A is the fifth new ALS gene discovered since the 2014 Ice Bucket Challenge through large, big data consortia focused on genetic identification and research supported by The ALS Association. It joins other genes, C21orf2, TUBA4A, TBK1, and NEK1, which ranks among the most common genetic factors associated with ALS. Over 25 ALS genes have been discovered, so far, but the rate of discovery has greatly accelerated since the Ice



Bucket Challenge.

This unique collaborative effort of over 250 researchers was led by Dr. John Landers at University of Massachusetts Medical School and Dr. Bryan Traynor at the NIH. Data and samples were openly shared between numerous genetic studies to accomplish this important gene discovery. Here, researchers achieved genome-wide significance to confirm KIF5A through analyzing genetic data from over 101,000 samples using two distinct

approaches.

"This open-source and global collaboration has been the underlying goal for building these large initiatives," said Lucie Bruijn, Ph.D. MBA, chief scientist for The ALS Association. "It is only through these kinds of partnerships that we can accelerate the pace of research towards new treatments for ALS." - Dr. John Landers.

The KIF5A gene discovery gives researchers a promising new target for drug development. The more genes discovered, the more potential therapeutic targets. It also provides insight and contributes to a collective knowledge base into the many interactive pathways explaining motor neuron degeneration, which is the underlying cause of ALS.

Nuedexta Trial Demonstrates Promising Results Impacting Bulbar Function in ALS Patients

In the January 9th issue of *Neurotherapeutics*, Dr. Richard Smith, Director of the Center for Neurologic Study in La Jolla, Calif. published promising results of a phase II trial testing the effect of Nuedexta on bulbar function. Overall, he and his co-authors found that Nuedexta had a significant palliative effect on speech, swallowing and salivation in people living with ALS. The ALS Association contributed to the funding of this trial.

Nuedexta is an oral medication that is composed of a combination of dextromethorphan and quinidine (DMQ). In 2011, this medication was approved for the treatment of the pseudobulbar affect (PBA), which is manifested by difficulty with emotional control, including inappropriate tearfulness and laughter. This is a common finding in ALS. Since approval, ALS patients on Nuedexta, along with their caregivers and physicians, have reported improvements in speech and

swallowing and the ability to control oral secretions. Following up on these unique reports, the ALS Association funded a Phase II trial to confirm whether Nuedexta favorably impacts bulbar function in people living with ALS.

Note: The bulbar muscles are muscles in the face and neck that control speech and swallowing. People with bulbar dysfunction show difficulty speaking and swallowing, along with having excess salivation. These issues can lead to problems eating, communicating with others and can cause discomfort.

The controlled clinical trial convincingly demonstrates the ability of Nuedexta to enhance speech, swallowing and the ability to manage oral secretions in patients with ALS. Interestingly, patients with and without pseudobulbar affect responded to treatment. It is important to note that Nuedexta did not improve motor or respiratory function, suggesting that Nuedexta specifically impacts bulbar

function. Based on this, one can conclude that not all of the nerve cells affected by ALS are the same. In this case, nerve cells that innervate the muscles involved in speech and swallowing are qualitatively different than nerve cells that innervate muscles of the upper and lower limbs. Taken together, this study suggests that symptomatic treatments may offer a window into understanding and ultimately treating ALS.

"I am pleased we were able to support this trial as a part of the TREAT ALSTM portfolio. The treatment approach could have a significant impact on the quality of life for people living with bulbar ALS," said Lucie Bruijn, Ph.D. MBA, Chief Scientist, The ALS Association. "We are eager for Nuedexta to reach all patients that may benefit as quickly as possible."

For the latest information on ALS research, visit alsa-stl.org.

Walk to Defeat ALS®



The Walk to Defeat ALS is the #1 way to empower yourself and to lend support to those fighting or caring for someone with ALS. Help us reach our goal of \$615,000 this year!

Springfield, IL | Southwind Park, June 16

Registration, 9 a.m. | Walk 10 a.m.

St. Louis, MO | Forest Park, June 23

Registration, 8:30 a.m. | Walk 10 a.m.



UNLOCK ALS - Connect with our community

New to the Walk this year is Unlock ALS – a way to visually symbolize why each of us are participating in the Walk to Defeat ALS®. Each person that attends the Walk will receive a key with a color specific lanyard to wear at the event. There are four different colors of lanyards; yellow indicates that you are a person with ALS, blue means you are walking for someone with ALS, red indicates that you are there to support the fight and the cause, and white means you have lost someone to ALS. During the opening ceremony we'll call for everyone to hold up their keys in celebration of the hope we have to unlock the mysteries of this disease. Additionally, participants can write a personal message on a paper key that will hang on display in our tribute tent.

Dowd Bennett LLP Presents the 2018 Walk to Defeat ALS



We are pleased to announce that Dowd Bennett LLP will be returning for the third year as the Presenting Sponsor for the 2018 St. Louis Walk to Defeat ALS. The firm is continues to suport partner Kelly Murrie and her Walk team, Team Tammy Hardy.

Kelly walks in memory of her sister, Tammy Hardy, who lost her six-year battle to ALS in 2008. Kelly's drive and passion for the St. Louis Walk to Defeat ALS has not diminished in the ten years she has been walking. Quite the opposite, she has increased her team membership and donations each year.

"I walk because it's what she would do - not for herself but for every other patient and family. I walk for the thousands of steps she didn't get to take," Kelly says.

Thank you Walk to Defeat ALS® Sponsors!

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DOWD BENNETT LLP

Springfield, IL Presenting Sponsor

**The Jane and Mark
Calmes Family**

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Express Scripts, Alliance Rehab, Missouri Foundation for Health

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. If you're interested in hosting an event of your own, please visit www.alsa-stl.org. We would like to acknowledge the following events held December 2017 through March 2018.



Phillip-a-looza

Phillip-A-Looza is a two night concert event held at the Old Rock House showcasing some of the best local musicians and bands in the area. The event is held in memory of Phillip Wright, who lost his battle with ALS in 2006. A portion of the concert's proceeds go to the ALS Association St. Louis Regional Chapter. This year we received over \$1,200!

Hiking the Appalachian Trail to Stomp Out ALS

Tim Pfeiffer is trekking almost 2,200 miles across 14 states to raise money for ALS. He's hiking the length of the Appalachian Trail in his father, John Pfeiffer's memory, and to honor those still fighting ALS. His goal is to raise a dollar for every mile he hikes for a total of \$2190.90!



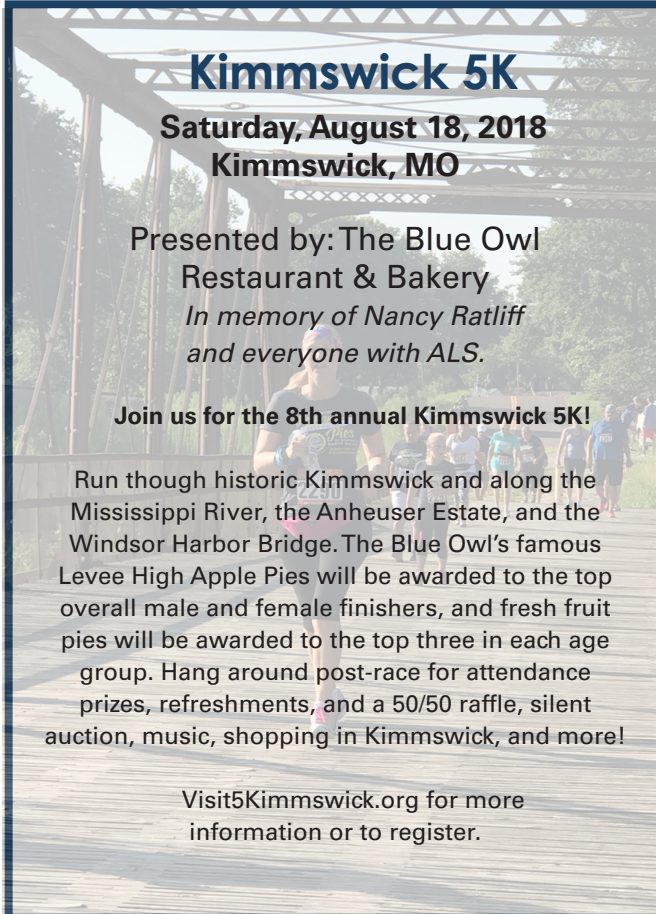
Creve Coeur St. Paddy's Day

For the second year in a row, the St. Louis Regional Chapter has had the pleasure of being selected beneficiary of the St. Paddy's Half Marathon and 7K. The race took place on Sunday, March 11th at Creve Coeur Park with over 1,200 people in attendance and we were awarded over \$2,600. Thank you to all of the volunteers that gave their time and energy in the freezing sleet and snow to help make this event a HUGE success!

Hogan's Heroes

The Hogan family hosted their annual St. Patrick's Day Parade fundraiser in memory of Mary Hogan. Thank you for being such loyal and fun supporters!





Kimmswick 5K
Saturday, August 18, 2018
Kimmswick, MO

Presented by: The Blue Owl
 Restaurant & Bakery
*In memory of Nancy Ratliff
 and everyone with ALS.*

Join us for the 8th annual Kimmswick 5K!

Run through historic Kimmswick and along the Mississippi River, the Anheuser Estate, and the Windsor Harbor Bridge. The Blue Owl's famous Levee High Apple Pies will be awarded to the top overall male and female finishers, and fresh fruit pies will be awarded to the top three in each age group. Hang around post-race for attendance prizes, refreshments, and a 50/50 raffle, silent auction, music, shopping in Kimmswick, and more!

Visit 5Kimmswick.org for more information or to register.



SAVE THE DATE!
Southern Illinois Miners
Walk and Awareness Night
Saturday, August 18, 2018
Rent One Park




SAVE THE DATE **MONDAY**
AUGUST 20, 2018

Sunset Country Club
 9555 S. Geyer Rd.
 St. Louis, MO 63127

NEW COURSE!

Swing for a CURE
 The ALS Association St. Louis Regional Chapter

www.alsa-stl.org/golf_tournament
npottebaum@alsastl.org



ICE BUCKET BASH
11.16.18
Four Seasons Hotel St. Louis

We're doing it all again – putting it on ice with five new celebrities! Don't miss this ice-themed bash with a carnival atmosphere – you won't find the same old boring chicken dinner at this party!

For more information, contact Andrea Flanigan,
aflanigan@alsastl.org or
 314-432-7257

UPCOMING EVENTS

Walk to Defeat ALS®

Springfield, IL
Saturday, June 16, 2018
Southwind Park

St. Louis, MO
Saturday, June 23, 2018
Forest Park

Kimmswick 5k

Saturday, August 18, 2018
Blue Owl Restaurant & Bakery
Kimmswick, MO

Swing for a Cure Golf Tournament

Monday, August 20, 2018
Sunset Country Club

Ice Bucket Bash

Friday, November 16, 2018
Four Seasons Hotel St. Louis

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



ALS ASSOCIATION St. Louis Regional Chapter

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JOHN BURROUGHS ALS CLUB



Middle school students from John Burroughs ALS Club spent an afternoon last winter spreading holiday cheer and helping with household chores as part of their club's annual project day. The students and chaperones raked leaves, wrapped presents, put up Christmas decorations and did chores for eight different families all over the region! Many, many thanks to this incredible group of kids, teachers and parents who give of themselves every year to make the holidays a little brighter for people battling ALS.