ALS ASSOCIATION
Greater Chicago Chapter

2017 YEAR IN REVIEW

FIGHTING LOU GEHRIG'S DISEASE

Serving Central Illinois, Greater Chicagoland, and Northern Illinois

CREATE A WORLD WITHOUT ALS

The Story of the Sunflower

Sometimes the quietest people have the loudest voices. That is especially true of Shirley (Hoffman) Schmelzle, whose voice has been all but silenced by ALS, but who still manages to have her message of ALS awareness heard.

Diagnosed with ALS in 2009, the former department store executive launched a campaign to adopt the sunflower as the official symbol of hope for those battling ALS. The goal of the sunflower symbol is to provide a simplified and consistent external public image representing ALS Awareness that is easy to recognize and visually unifying.

"When I was first diagnosed with ALS, I was struck by the fact that there is no common image promoting ALS Awareness," says Shirley. "The sunflower," she explained, "stands tall and strong, ever hopeful and ever reaching higher. Sunflowers grow in clusters and support each other as they grow, just as family, friends and community offer support to those who live with ALS." It was designed to evoke a sense of hope, grace and dignity and to reflect the support that those living with ALS receive from their team of supporters.

THE GREATER CHICAGO CHAPTER

Established in 2004, The ALS Association Greater Chicago Chapter is fighting Lou Gehrig's Disease on every front. We are the leader in ALS care, advocacy, research and education. We are proud to serve the Central Illinois, Greater Chicagoland, and Northern Illinois ALS Communities.

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.

CORE VALUES

The ALS Association Core Values:

COMPASSION

INTEGRITY

URGENCY

DEAR FRIENDS,

One of the most important foundations for any organization is a clearly defined purpose. The ALS Association Greater Chicago Chapter was established with the purpose of providing care services, advocating and investing in research to find treatments and a cure for ALS.

Since 2004, we have experienced unprecedented growth for the need of our services throughout our expanding service territory. We have established ALS Multidisciplinary Clinics in partnerships with world-renowned hospitals, achieved success with strategic advocacy efforts, and developed significant relationships with partners in the fight against ALS.

We are privileged to serve our community with purpose and dedication. Join us by pledging your time, talent and treasure as we work together to fulfill our mission. We are confident that significant strides will be made in the areas of research, advocacy, and care, and that our combined efforts will lead to a cure!

Warm Regards,

Julie M. Sharpe
Executive Director | ALS Association Greater Chicago Chapter

This year was yet another year of hope and unity for the ALS Community. While we still face the harsh realities of this disease, we know that as each day passes we get closer to long term effective treatments and a cure. I am truly grateful for this continued progression forward.

I had the pleasure of spending the day recently with some of our amazing Ambassadors and was truly humbled by all I heard and saw. I feel that our community gathers people whose souls are truly selfless and are dedicated to serving our families and patients in whatever way they can.

Please know as you read this, wherever you are in the stages of your journey, regardless of whether you are a person living with ALS, a caregiver, a family member, a friend, neighbor, or concerned citizen, the Greater Chicago Chapter is here for you every step of the way. I assure you, if you need support, regardless of how you like to receive it, we have a staff member, volunteer, or families that are all hoping you will reach out in your time of need. Together is how we will get through this and beat this disease once and for all. Warmest wishes for a blessed 2018!

Christine Churchill Burke
2017 Chapter Board President | ALS Association Greater Chicago Chapter

IMPACT OF OUR MISSION

"I've been involved with the ALS Chicago Chapter for over three years now as I've helped a dear friend living with this disease. As I've become more involved with the care of my friend, I've found myself becoming more involved with the chapter. As I've become more involved with the chapter, I've found myself wanting to do more. My friend's only request when she was diagnosed, was for us to help her help others who suffer from ALS. This has been an easy request as the Chicago chapter, it's staff, ambassadors and all who support it have become family. Everyone is working towards a common goal and the support is immeasurable. I can't imagine not being a part of this Association and I'm proud to be an Ambassador to support, educate and advocate for all those who deal with this disease."

KIM McQUEEN
FRIEND OF ALS PATIENT
CHAMPAIGN, IL

"Joumana and The ALS Association Greater Chicago Chapter were a godsend to our family at an incredibly difficult time. From arranging appointments with specialists at the onset of my sister's diagnosis and providing in-home assessments so that we properly planned for necessary accommodations, to introducing us to an amazing caregiver, we would never have been able to provide the loving and supportive environment that my sister deserved in the wake of her illness. Joumana skillfully guided both the patient and her extended family throughout this entire journey and we will be forever grateful for her expert knowledge, unwavering dedication, and compassionate care shown to us."

MARY ANN MCKEVITT
SISTER OF ALS PATIENT
ORLAND PARK , IL

"As we continue to face the challenges of ALS, it has become a great comfort to know we can lean on The ALS Association Greater Chicago Chapter. Most recently they delivered a Hoyer lift to aid us in the transfer process. It has been a tremendous help and we are forever grateful that our immediate needs are always met by Joumana and the committed staff. Words alone would be inadequate for expressing Doreen's and my thanks for allowing us the opportunity to join in on the advocacy experience. We have made new friendships that will last forever."

FRANK DODERO
INDIVIDUAL LIVING WITH ALS
NAPERVILLE , IL

IN THEIR OWN WORDS

"The ALS Association Greater Chicago Chapter has helped the Central Illinois region not only raise awareness of this disease, but also provide countless resources to those fighting ALS as well as their family members. The volunteers and employees of the Chapter are always open to hearing new ideas and finding what works best for our communities. I'm thankful for the caring and knowledgeable employees of the Greater Chicago Chapter; they partner with our community to help bring an end to this disease."

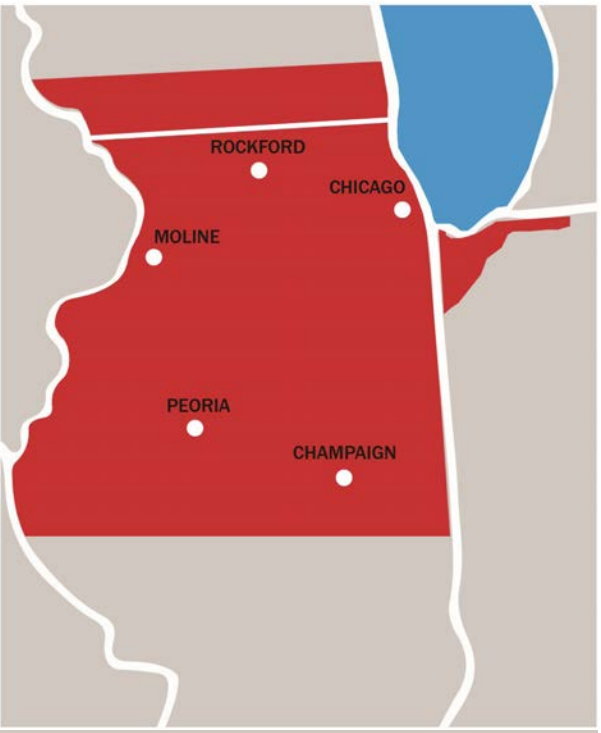
"The support group hosted by the Greater Chicago Chapter is my place to go for information on ALS since my brother who has ALS lives in another state. I don't know what I would have done without the support of this group. Thank you for providing it! I really appreciate all the time and energy put forth."

"Our lives would have been unimaginable without the services and support from the ALS Association Chicago Chapter."

"Two years ago, we reached out to the Greater Chicago Chapter seeking some insights after my Dad's diagnosis with ALS. The team has been unbelievable in the dedication and support to our family. It inspired us to "give back" through getting engaged in many volunteer opportunities the organization sponsors in their tireless efforts to find a cure."

CARE SERVICES

The ALS Association Greater Chicago Chapter provides exceptional care services, the latest resources and information, and premier programming for Persons Living with ALS, their families and caregivers. We are proud to currently serve in Central Illinois, Greater Chicagoland area, Northern Illinois, and Northwest Indiana.



The ALS Association Greater Chicago Chapter's service area covers Central Illinois, Greater Chicagoland, Northern Illinois, and parts of Wisconsin and Northwest Indiana.

There is no cost to persons living with ALS and their families for any of the services we provide.

PROFESSIONAL IN-SERVICE PRESENTATIONS

In-services are provided by our Care Services Team to an array of health care providers, educating them on what ALS is, and how to care and support those living with ALS.

RESPITE CARE PROGRAM

The demands on family caregivers can be enormous, progressive and overwhelming. Our Chapter's Respite Care Program enables caregiver relief by making it possible for families to receive intermittent care for the person with ALS from a third party caregiver, allowing caregivers to take care of themselves and provide their best to loved ones.

ALS ONLINE COUNSELING SERVICES PROGRAM

Our Chapter is now offering a limited number of sessions for each patient/caregiver we serve to be able to meet with a Licensed Clinical Social Worker to address issues related to depression, anxiety, grief, adjustment issues, and other emotional struggles those affected by ALS may be experiencing through an easy online format.

CAREGIVER BOOT CAMP

In 2017, our Chapter hosted three Caregiver Boot Camp sessions. The Boot Camp provides education about the role of a caregiver, how to use common pieces of medical equipment and provide an opportunity to ask questions to better prepare them in assisting their loved one living with ALS. In 2018, we will be expanding our Caregiver Boot Camp program.

HOME VISITS

Care Services Coordinators provide home visits, supporting the care management of individuals living with ALS and act as the liaison between them and their medical team. Home visits encompass home safety evaluations, disease education, and timing and training of adaptive equipment.

ADAPTIVE EQUIPMENT LENDING PROGRAM

One of the most utilized programs, the Adaptive Equipment Lending Program provides items that assist with mobility and communication, improving the quality of life for those individuals living with ALS. It is through the generosity of many donors who have either donated equipment or funds to our chapter that allows us to invest in much needed equipment for those we serve.

SUPPORT GROUPS

Monthly support groups in different geographical locations are offered to those living with ALS, their family members and caregivers. The groups are an opportunity to join in fellowship, learn about new information and resources, and provide or receive support and encouragement.

"Since my husband's diagnoses in May of this year, I have been reading and reading, and talking and talking with people about how they deal with the ALS disease and the changes that it brings to their families. What I have found out for sure is that there are no two families the same and having the bonding time with other families, in a very casual environment (at the Boot Camp) has given me great comfort. From asking what I think are stupid questions to finding common ground with how things work at our doctor's office (when you share the same doctor) has really made a difference for me and my family. Considering doing this again (and soon) as I feel it was one of the most beneficial events you offer. It's much different than a support group and job well done!"

LORA McKEE,
OREGON, IL
CAREGIVER BOOT CAMP ATTENDEE

SAVE THE DATES

2018 CAREGIVER BOOT CAMP

CHICAGO | March 24th

NORTHERN IL | May 5h

CHICAGO | August 25th

CENTRAL IL | November 10th

ALS MULTIDISCIPLINARY CLINICS

The ALS Multidisciplinary model provides high-quality, state-of-the-art care and clinical management along with access to the latest treatments for individuals living with ALS. It brings together physicians including neurologists and pulmonologist, pharmacists, occupational and speech therapists, nutritionists, social workers, and home palliative care staff that can provide comprehensive, specialized, sensitive care that addresses all of the needs in one place at one time. Research suggests that patients who receive treatment at an ALS Multidisciplinary Clinic live longer and have a higher quality of life.

The ALS Association Greater Chicago Chapter financially supports 6 ALS Multidisciplinary Clinics including two Certified Treatment Centers of Excellence. In 2017, there were 621 clinic visits by individuals living with ALS who are served by the Greater Chicago Chapter. Our Care Services Coordinators are integrated into the weekly, bimonthly and monthly clinics as liaisons between individuals and their medical team.

THE UNIVERSITY OF CHICAGO MEDICINE

ALS ASSOCIATION CERTIFIED TREATMENT CENTER OF EXCELLENCE

"We at the University of Chicago are indebted to the ALS Association for all it does both nationally and locally for ALS patients. Our ALS Association Certified Treatment Center of Excellence is helped by the participation, invaluable guidance, and coordination of experts from the ALS Association Greater Chicago Chapter of the ALS Association. In addition, the ALS Association has provided funding for ALS research grants to two investigators in the Department of Neurology at the University of Chicago".

Raymond Roos, M.D.

UNIVERSITY OF ILLINOIS Hospital & Health Sciences System
Changing medicine. For good.

ALS ASSOCIATION CERTIFIED TREATMENT CENTER OF EXCELLENCE

"We feel privileged to have the opportunity to care for patients with ALS in our ALS Association Certified Treatment Center of Excellence. We strive to provide the highest level of multidisciplinary care and support for all patients with ALS and their families."

Charles Abrams M.D., Ph.D.

"We appreciate the support from the ALS Association Greater Chicago Chapter in helping us to establish a comprehensive ALS Clinic at Rush University Medical Center. We look forward to the future growth of our clinic and we are excited to partner with the Chapter in helping our patients battle ALS."

Madhu Soni, M.D. and Matthew N. Meriggioli, M.D.

"This year has been a very challenging time for clinic and local ALS community with the loss of many wonderful people. The ALS Association has continued to be such a wonderful support for our clinic and especially our patients. Our clinic could not exist without the education and outreach they provide for so many people. Thank you for simply being awesome."

Shawn Wallery, M.D.

"Since our inception in June 2016, the NorthShore ALS clinic has been honored to care for patients from throughout North and Northwest Chicagoland. Our multidisciplinary clinic is currently located in our NorthShore Neurological Institute clinic in Glenview, IL. With the generous support of the ALS Association Greater Chicago Chapter, we are able to provide comprehensive care for patients and families living with ALS."

Octavia Kincaid, M.D.

"The Hines VA ALS clinic care team and the ALS Association Greater Chicago Chapter have worked well together for several years to bring the best possible comprehensive care to veterans with ALS. The Chapter assists with referrals into the VA system for expedient access to care and benefits. They also provide ongoing care to veterans with a community-based support system and resources that compliments the care they receive from the VA. I look forward to continued future collaboration with the Greater Chicago Chapter in assisting to bring the best possible care to the veterans!"

David Kvarnberg, M.D.

ADVOCACY

The ALS Association Greater Chicago Chapter, in partnership with the ALS Association's Public Policy Department, tirelessly advocates for investments in research, access to equipment, quality of life, increasing benefits, and caregiver support to provide people with ALS and their families an active and strong voice in the nation's capital and state capitals across the country. Every year, we head to Washington, D.C. to participate in the ALS Association's Public Policy Conference and National ALS Advocacy Day where we take our concerns and priorities to members of Congress and the Senate to garner their support.

The ALS Association hosts its annual ALS Public Policy Conference and Advocacy Day in May. In 2017, a 17 member delegation, including individuals living with ALS throughout our service territory, participated in this year's conference. During our "Day on the Hill", members of the delegation met with representatives from the Senate and Congress sharing their personal stories about living with ALS, the impact it has had on their lives and encouraging support for initiatives that will impact the ALS Commmunity.

"Thank you so much for the opportunity to join you in D.C. It was a great getaway for me but also gave me a cause to focus on while I struggle to find Holly again. You were all so kind to me and made me feel like part of an amazing group. Know everything you do makes a difference to those fighting ALS."

HOLLY WILDE
CARTHAGE, IL

IMPACT ON ADVOCACY

We bring the ALS community together to speak with one voice to increase awareness, advocate for research funding, and educate legislators, impacting thousands of people with ALS and their families. This advances 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.

ALS ASSOCIATION

BIGGEST SUCCESSES IN 2017

$10M NATIONAL ALS REGISTRY

Led the charge to secure *$10 million in appropriations* for the National ALS Registry** to find treatments and cure for ALS

Spearheaded effort to pass bipartisan ALS Disability Insurance Access Act to waive 5-month wait for people living with ALS; 104 Representatives and 24 Senators support to date

$10 MILLION

Successfully protected the ALS Research Program at the Department of Defense (DoD)** resulting in $10 million in appropriations and ensuring its place at the DoD

Played a key role in ensuring people with ALS have access to wheelchairs and complex rehab technology by applying legislative pressure on the Centers for Medicare and Medicaid Services. A big advocacy success

NIH $55M

Pushed for more ALS funding by the National In-stitutes of Health (NIH)** which spent $55 million in FY 2017 on ALS research

Advocated for continued and permanent access to speech generating devices in all settings by cultivating support from 91 Representatives and 10 Senators for the Steve Gleason Enduring Voices Act*

Joined with other leading patient organiza-tions to protect the rights of people living with ALS and other pre-existing conditions or who were on Medicaid to ensure access to health care

770+ MEETINGS

11 ACTION ALERTS

Accomplished over 770 meetings with Members of Congress from our annual Advocacy Fly-In and National Advocacy Conference and sent 11 action alerts to more than 16,000 ALS Advocates generating more than 17,485 messages to Congress

Initiated planning for a multi-year effort to educate and influence Congress and Administration officials to remove complex barriers to Medicare home health for people living with ALS

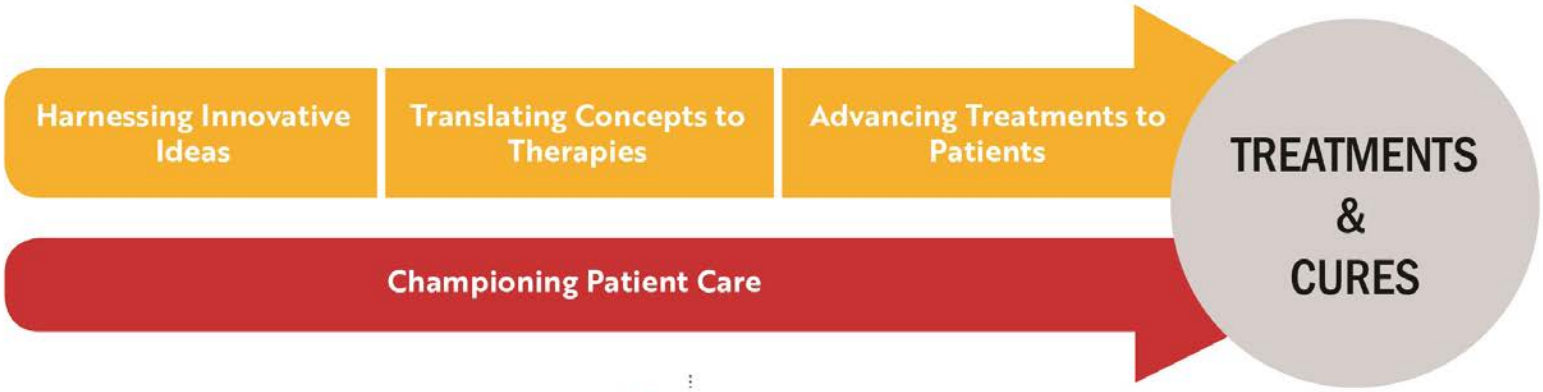
*Bill is still moving through Congress
**Appropriations expected to be passed by end of year

BECOME AN ADVOCATE TODAY

Register at www.alsachicago.org

RESEARCH

The ALS Association Greater Chicago Chapter is one of the national leaders in ALS research funding; donating more than 10 million dollars towards finding effective treatments and a cure for Lou Gehrig's Disease. Our contributions support world-wide research efforts. We are the leader in the State of Illinois in funding advanced new discoveries and treatments which have shed new light on the complex genetic and environmental factors involved in ALS.



4 NEW GENES identified since the ALS Ice Bucket Challenge to develop new therapies

126+ FUNDED GLOBAL RESEARCH PROJECTS IN 8 COUNTRIES

9 *global strategic initiatives*

6 new postdoctoral fellows funded in 2017

$18 MILLION *current research budget*

The ALS Association is the highest nonprofit research funder in the U.S.

$89+ MILLION *dedicated to research since the ALS IBC to advance treatments and a cure*

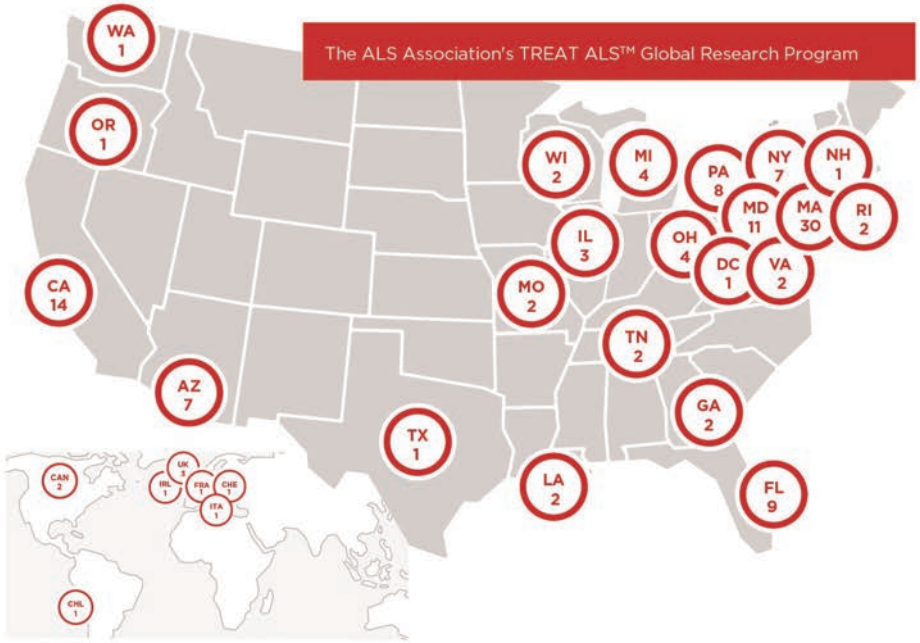
55+ actively recruiting ALS clinical trials

two potential new antisense drugs and numerous other drugs on the horizon aimed to slow or stop the progression of ALS

2 Clinical Scientists Funded in 2017

OUR ACHIEVEMENTS

To date, The ALS Association has funded more than $150 million in ALS research. Currently, we are funding over 126 active research projects in eight countries, all selected through our competitive peer review process, involving top ALS scientists. We are the largest private funder of ALS research worldwide. Our unrelenting focus has resulted in some of the greatest ALS research discoveries in history. From the earliest stages of our program, The ALS Association has recognized novel approaches that have led to significant ALS research breakthroughs.



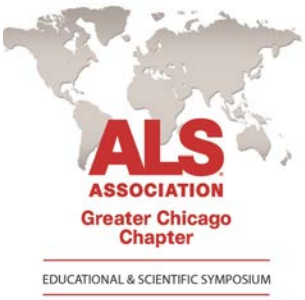
INNOVATION IN ALS

THE FDA took an unprecedented step when they did not require clinical trials in the U.S. In 2017 the FDA approves the first ALS drug in 20 years, Radicava. With our ALS Drug Development Guidance document in hand, with ALS Association's ALS Advocacy team worked with the FDA to speed up the approval process.

"The ALS Association is committed to supporting biomarker discovery. Identifying biomarkers is an extremely important step in the drug development pipeline to accelerate the discovery of novel treatments and a cure for ALS. We support a number of exciting biomarker research studies in addition to he TDP-43 Biomarker Grand Challenge, all aimed at pioneering and moving the ALS biomarker field rapidly forward."

DR. LUCIE BRUIJN
CHIEF SCIENTIST

EDUCATIONAL & SCIENTIFIC SYMPOSIUM



The 7th annual Patient & Caregivers Educational Symposium provided a great opportunity for individuals living with ALS, caregivers, and advocates to gather together, learn more about research, treatments, and management of ALS.

This year's Vendor and Service Provider Expo brought together 22 vendors from a variety of industries. The program focused on caregivers and caregiving and brought together an expert panel to provide an update on research, tools to manage emotional distress, and highly valuable information about the insurance options patients have.

120
Educational & Scientific Symposium Attendees

20
Researchers & Scientists

22
Care Service Vendor & Partner Exhibitors

BREAKFAST ROUNDTABLE

The Breakfast roundtable brought together some of the top researchers and scientists in the ALS community. The discussion was led by Chief Scientist of the ALS Association, Lucie Bruijn, Ph.D., MBA, with the focus of the discussion being Advancing ALS Research. One of the highlights was a discussion lead by Biogen's Chris Henderson on the developments on the horizon.

VENDOR EXPO

The Vendor and Service Provider Expo allowed attendees to engage with long term community partners of the Greater Chicago Chapter who understand ALS-specific needs and can provide durable medical equipment and services to the ALS Community. This year we had 22 Vendors present representing industries of respitory care, pharmaceuticals, home health care, mobility and much more!

EXPERT PANEL

The Panel consisted of experts in diverse fields to provide insight on managing ALS. Chief Scientist of the ALS Association, Lucie Bruijn, gave an update on worldwide research and the promising clinical trials currently taking place. Dr. Raymond Roos, MD, Director of the University of Chicago ALS Certified Treatment Center of Excellence, explained the advancements of a similar motor neuron disease and its effect on new treatments that are on the horizon for ALS. Allen Sabey, PhD, LMFT, briefly discussed the common emotional experiences of caregivers and care recipients, and briefly explained techniques for managing emotional distress. Greater Chicago Chapter Care Services Coordinator, Kellie Branch-Dircks, MSW, LCSW, closed with simplifying the different insurance options.

SAVE THE DATE

8TH ANNUAL EDUCATIONAL & SCIENTIFIC SYMPOSIUM

November 7, 2018

Rush Medical Center

ALS & THE MILITARY

Military Personnel are two to four times more likely to be diagnosed with ALS than the general population. The Greater Chicago Chapter has an affinity for our veterans living with ALS. We are grateful for their service to our country and want to ensure they have access to the benefits they earned defending our freedoms.

The Greater Chicago Chapter is partnered with the Edward D. Hines VA Hospital to assist in the development of an ALS Multidisciplinary Clinic. Dr. David Kvarnberg is the Clinic Director and Audrey Scafidi, LPN, ALS Association Greater Chicago Chapter Care Services Coordinator, serves as the Chapter liaison attending clinics and support groups.

HONORING OUR HEROES

The ALS Association Greater Chicago Chapter's Medal of Valor recognizes a veteran living with ALS who exemplifies the following qualities of character: Courage, Fortitude, Spirit and Valor. This year Al Houston was the recipient of this award.

"It was an honor to receive the Medal of Valor from the ALS Association. I was extremely humbled to be selected to receive the award. It is my faith in God that enables me to exhibit the attributes the award embodies, such as courage and fortitude. When asked by others 'How do you maintain such a positive attitude?' my standard response is 'I'm in a win-win situation. If I overcome ALS, I win because it will give me the opportunity to spend additional time making a positive difference and adding value to the lives of others. However, if I were to succumb to the disease, I would still win because I have the assurance that I will spend eternity with God.' This is what enables me to stand strong, encourage others and live a life that is full of joy even in the midst of my challenges. Again, I would like to thank the ALS Association for honoring me with the Medal of Valor. I pray I will always live up to all that the award embodies."

AL HOUSTON
INDIVIDUAL LIVING WITH ALS
OLYMPIA FIELDS, IL

AWARENESS

The ALS Association Greater Chicago Chapter is committed to educating the public about what ALS is, the effect on the families, and what they can do to become involved in order to support our mission and the ALS Community.

May is national ALS Awareness Month and for the past six years the Greater Chicago Chapter has been on the forefront in creating some of the most meaningful awareness campaigns in Illinois and beyond. Our CURE 90/90 program was created to educate the public, not on the actual numbers of those who are diagnosed with ALS, but the extraordinary incidence with which the disease occurs. Every 90 Minutes Someone is Diagnosed with ALS and Every 90 Minutes Someone is Lost to this Terrible Disease.

BREAKTHROUGH ALS

Our annual ALS awareness event, Cure 90/90, was held May 22nd at Daley Plaza in Chicago. The theme, Breakthrough ALS, was inspired by "Team Paul Mitchell" karate expert, Kevin Thompson, and his battle with ALS. Black Belt karate champion, Dan Kersten, joined us in the plaza to bring awareness to ALS in honor of his friend and mentor Kevin. It was a powerful day of board breaking to symbolize the much needed breakthrough that ALS patients are hoping for.

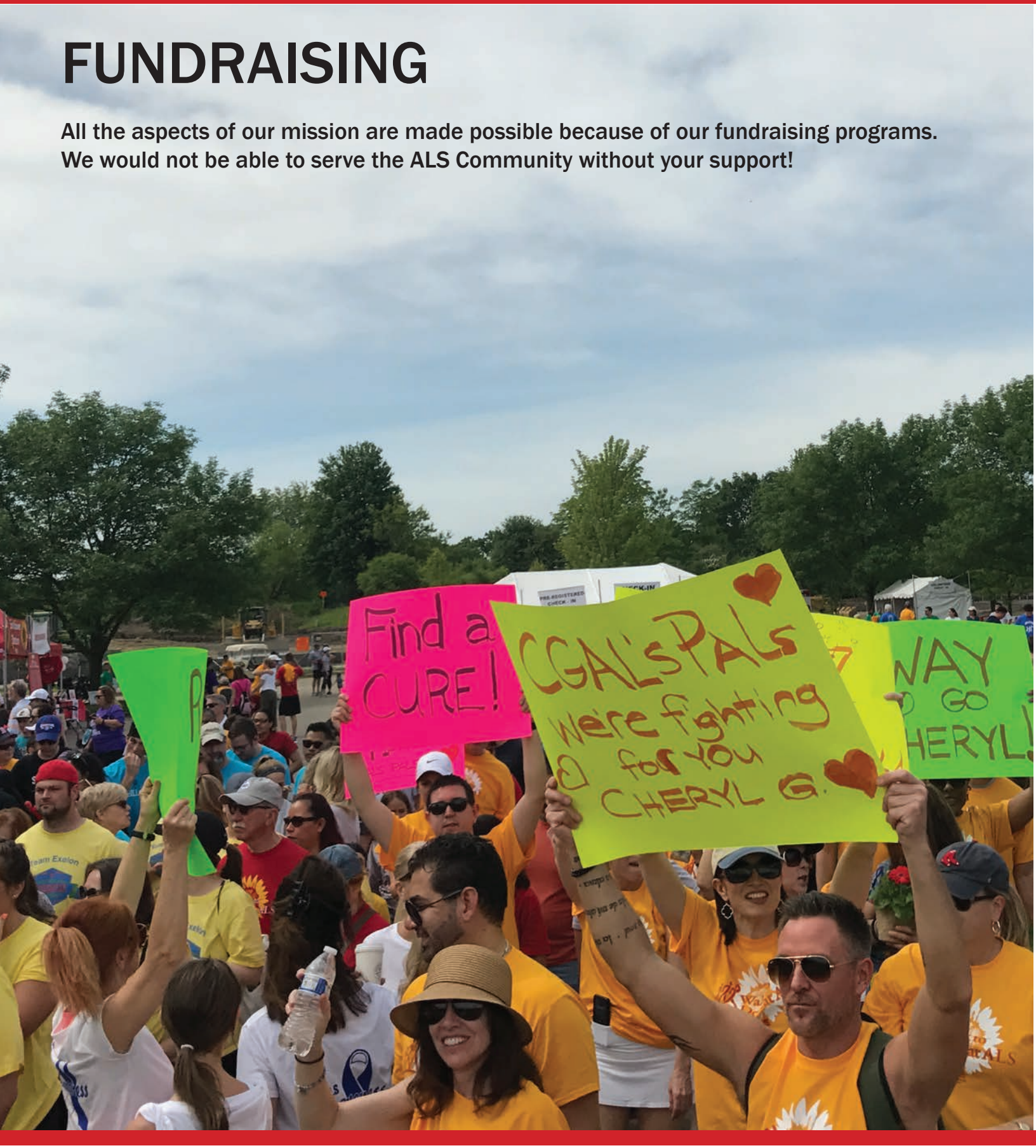
SAVE THE DATE
CURE 90/90

May 21st, 2018

Daley Plaza - Chicago

FUNDRAISING

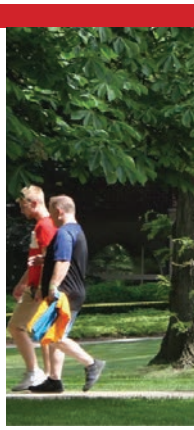
All the aspects of our mission are made possible because of our fundraising programs. We would not be able to serve the ALS Community without your support!



IronHorse Ball

Thank you to all who attended and supported the 2017 IronHorse Ball.

WALK TO DEFEAT ALS



The Walk to Defeat ALS® is our most significant source of funding for all the services we provide to the ALS Community. Because of our Walks, we are able to offer essential services free of charge, fund the research that will one day find the cure, and advocate on behalf of and empower those living with ALS.

Our four Walk to Defeat ALS Events - Chicago, Peoria, Champaign, and Rockford – have raised more than $864,000 to further our mission!! Collectively, on our Walk Days, we had 217 teams nearly 3,300 walkers, and over 500 volunteers!

2017 TOTALS

GREATER CHICAGO WALK

$549,000 Raised
1844 Participants
131 Teams

PEORIA WALK

$125,000 Raised
422 Participants
29 Teams

CHAMPAIGN WALK

$63,725 Raised
325 Participants
17 Teams

ROCKFORD WALK

$142,000 Raised
588 Participants
40 Teams

TOP TEAMS

Team Exelon	$52,346
Gronk's Grace	$47,034
Team Rapp	$40,085
Team Martel 2017	$30,200
Pam's Posse	$20,240
Swing Fore a Cure	$15,687
The FRANKfooters	$25,800
Queen Ronna and Her Jesters	$25,724
Brucester's Brewsters	$24,804
Swing Fore a Cure	$15,687
CGal's Pals	$15,333
Page's Posse	$14,425

I WALK TO DEFEAT ALS BECAUSE...

"I want to support the organization that does such a great job supporting my family while my wife is afflicted with ALS."

"The ALS Association was vital to our family during my mom's battle."

"This terrible disease should be wiped from this world! It took my love, my life, my best friend, my wife!"

"I care, I can and need to."

SAVE THE DATES
WALK TO DEFEAT ALS

GREATER CHICAGO
June 2, 2018
Cantigny Park - Wheaton

ROCKFORD
September 22, 2018
Rock Valley College

PEORIA
September 8, 2018
Dozer Park

CHAMPAIGN-URBANA
September 29, 2018
Meadowbrook Park

RUN TO DEFEAT ALS

On Sunday, October 8, 2017, 115 TeamALS charity runners took their marks on the starting line of the 40th anniversary of the Bank of America Chicago Marathon. Each of them not only put in the time and long months of training to get to that point, but in conjunction also raised funds for ALS. Together, the team raised $215,000!

It was a privilege for us at the Greater Chicago Chapter to get to know them and their personal stories. Most all members of the team had a personal connection to ALS and decided to run a marathon in honor or memory of a loved one - a family friend, coworker, neighbor, brother, mother, grandfather. We hold much admiration of our TeamALS members and feel fortunate to work with them on their journey and in the fight against ALS.

TOP TEAMS

Team ARG	$22,500
Love for Julie	$9,242
Sulentic Family	$6,020

TOP PARTICIPANTS

Michelle Moore	$35,660
Kim Hogen	$5,805
Katherine White	$5,285
Caroline Page	$5,080
Matthew McClain	$4,667
Tracey Kreiling	$4,522
Mike Sulentic	$4,300
Abbey Dyer	$4,300
Manjot Gill	$4,102
Cari Radziewicz	$4,005

"I was three and my father thirty-one when ALS took his life. Last spring, when I turned forty-five I realized I'm living years he didn't get. I wanted to honor him by celebrating them and challenging myself to live them well. Running my first marathon was certainly a challenge, but running with TeamALS to support the work of The ALS Association took it to a whole other level. I wasn't running on my own; other team members were running with me, and so were the friends and family who supported me and cheered me on. ALS is a terrible disease, but it has brought together amazing people from all walks of life, and I was so proud to be running with and for them all!"

JENNIFER OULD
CHICAGO, IL

"Running the 2017 Chicago Marathon was a challenge and a goal all within itself. But running with TeamALS opened my eyes to so many other things that are bigger than running. Namely love. This family is nothing short of AMAZING! Even while running and wanting to give up at certain times of the race, it almost seemed as though at strategic times in the race different TeamALS members would be right next to me encouraging me to go on. With that said, with God inside of me, my training in front of me, and my TeamALS family and friends behind me, we all came out VICTORIOUS. This is why I ran for love and for dad."

LUVELL STEPTER
CHICAGO, IL

SECURE YOUR SPOT RUN TO DEFEAT ALS

If you are interested in being part of TeamALS 2018 for the Bank of America Chicago Marathon on October 7, 2018, please contact **sarah@alsachicago.org**

THE ALS CLASSIC

The ALS Classic presented by The Hartford was once again a day for the books! The weather, fellowship and the golf made for an incredible day in the fight against ALS.

We are grateful to our corporate sponsors whose support is essential in making this spectacular event possible each year, including our presenting sponsor: The Hartford and its Chairman & CEO, Chris Swift. Thank you to Travelers Insurance for sponsoring the Cocktail Reception and Awards Ceremony, Hydratight for the luncheon and hospitality during play at the Classic Cantina and Tiki Hut, and to Allstate, one of our newest sponsors, for the beverage cart. We appreciate everyone who made a donation at the hospitality tent and for supporting the raffle, silent auction and the Flamingo Ball Drop.

The ALS Classic

SAVE THE DATE THE ALS CLASSIC

September 5th, 2018

Cog Hill Golf Course & Country Club

Make your commitment today to help us reach our 2018 goal of 50 foursomes and a second course - bit.ly/ALSClassic2018

COMMUNITY PARTNER EVENTS

COMMUNITY
An Event to Benefit
The ALS Association
Greater Chicago Chapter
PARTNER EVENT

Community Partner Events are fundarising activites coordinated and run by anyone who wants to support our Chapter in their own way. Individuals or groups can create a fun, unique, engaging event to raise both awareness and funds, which directly impacts the ALS Community we serve.

In 2017, there were 26 Community Partner Events held during the year. We continue to be amazed by what our supporters come up with and choose to do to benefit the cause!

LOOKING FOR IDEAS?

- Trivia Night
- Pub Crawl
- Lemonade Stand
- Volleyball Tournament
- Garage Sale
- Dress Down Day
- Basket Auction
- Olympic Games
- Cornhole Tournament
- Fantasy Sports League
- 3-on3 Basketball
- Block Party
- Bowling Event
- Car Wash
- Chili Cook-Off
- Pizza Party
- Give Back Nights
- Game Night
- Ice Cream Social
- Penny Drive

CREATE YOUR OWN

If you are interested in creating your own Community Partner Event, please contact jessica@alsachicago.org

COMMUNITY EVENT PROFILE

The Iron Horse Rally was held in August 2017 in honor of the ALS Community. Motorcycle enthusiasts had the opportunity to rally together in support of family members and friends. The day was glorious, with over 75 individuals gathering for a ride which ended at Paulie's in Aurora, IL for lunch and a raffle basket auction. The creation of the event was lead by Christine Church-Hill Burke, 2017 Chapter Board President, Mike Trafton and Patti Stockwell, Chapter Board Members, Peggy O'Connor, Chapter Care Services Coordinator, and Andrew Wasilewski, an individual living with ALS.

SAVE THE DATE
IRON HORSE RALLY

August 18, 2018

ironhorserallytodefeatals.org

VOLUNTEERING

ALS ASSOCIATION
Greater Chicago Chapter
Ambassador

AMBASSADOR PROGRAM

Ambassadors are key volunteers who have demonstrated commitment to the Chapter by their involvement in multiple capacities with passion for our mission and the people we serve. These 32 individuals give countless hours of their time answering the call to represent the Chapter at numerous community, corporate and organization events, in addition to the many Chapter sponsored events. They work tirelessly and enthusiastically raising awareness and funds, and advocating on behalf of the Greater Chicago Chapter. We are so grateful for the loyal devotion of our Ambassadors and their continued support and dedication to bettering the lives of those impacted by ALS.

"I became an Ambassador for the Greater Chicago Chapter in 2014. I lost my Mom to ALS in 2013 and it's a frustrating feeling when you can't 'fix it'. I became more involved and found that it's an honor to represent our Chapter which has such a positive impact on our local ALS community. Our ambassador community is determined, they motivate and inspire me to continue fighting even when it can be a tough reminder of the saddest part of my life. I have to keep fighting because my family has lost 9 people to ALS and I'm at high risk to get it. I advocate on a broader platform now to help people think about genetic research differently."

SAM MATUSIAK
CHICAGO , IL

Our Lou's Crew volunteer members come to us from all walks of life. Many are high school or college students looking to get involved in their local community, others have been personally impacted by ALS and want to make a positive difference in honor of their loved ones, and some are employee groups who are choosing to come together and use their resources for good. All of these folks are extremely valued by the Greater Chicago Chapter, and we are grateful for their continued support and engagement. It is only with them that we are able to sustain our programs and ensure success at the variety of events we host throughout the year that raise both funds and awareness for ALS.

In 2017, Lou's Crew volunteers donated over 2,500 hours of their time and talents to help in the fight against ALS. We are amazed by their generosity and commitment to the cause! Way to go, Lou's Crew!

BECOME A MEMBER OF LOU'S CREW

We love our Lou's Crew Volunteers! Get involved or engage your company, school, or corporation today! Contact: sarah@alsachicago.org

ALS ASSOCIATION GREATER CHICAGO CHAPTER STAFF

Julie M. Sharpe
Executive Director
2006 - Present

julie@alsachicago.org

Chris Johnson
Director of Operations
2013 - Present

chris@alsachicago.org

Kendra Albers
Walk to Defeat Program Director
2015 - Present

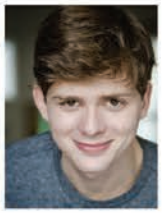
kendra@alsachicago.org

Jessica Dickman
Events and Marketing Coordinator
2016 - Present

jessica@alsachicago.org

Sarah Brandt
Volunteer Coordinator
Run to Defeat Program Coordinator
2012 - Present

sarah@alsachicago.org



Daniel Mozurkewich
Data Hygiene & Outreach Coordinator
2015 - Present

dan@alsachicago.org

Joumana Baroody, RN, BSN
Director of Care Services
2010 - Present

joumana@alsachicago.org

Peggy O'Connor, RN, BSN
Care Service Coordinator
2015 - Present

peggy@alsachicago.org

Audrey Scafidi, LPN
Care Services Coordinator
2014 - Present

audrey@alsachicago.org

Kellie Branch-Dircks, MSW, LCSW
Care Services Coordinator
2014 - Present

kellie@alsachicago.org

Gema Ramos, RN
Care Services Coordinator
2016 - Present

gema@alsachicago.org

Kaveri Bhatnagar, MA, CCC-SLP
Speech Language Pathologist
2014 - Present

kaveri@alsachicago.org

Stephanie Barb, CCC - SLP
Speech Language Pathologist
Central Illinois
2017 - Present

stephanie@alsachicago.org

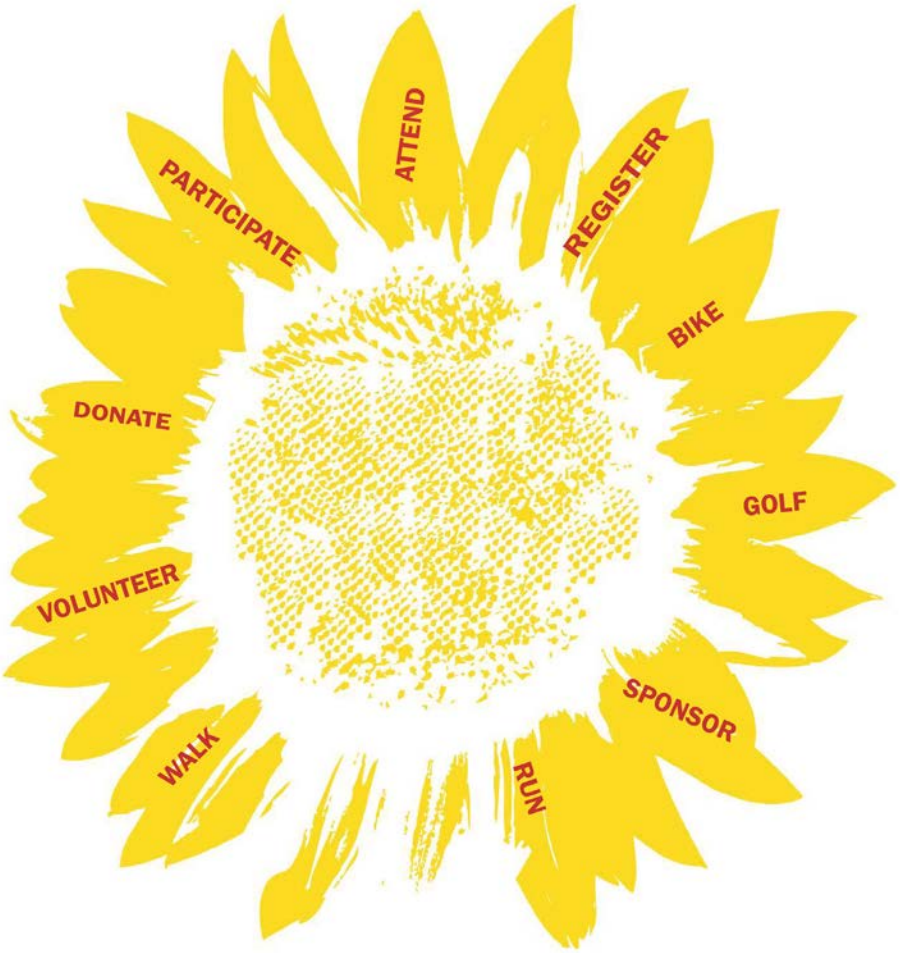
ALS ASSOCIATION
Greater Chicago Chapter

312.932.0000
alsachicago.org

220 W. Huron St., Suite 4003
Chicago, IL 60654

HOW WILL YOU BE INVOLVED IN 2017?

Make a commitment to yourself and to the ALS Community



THANK YOU for your tax-deductible contribution to the ALS Association Greater Chicago Chapter.

Name _____ Address _____
City _____ State _____
Phone _____ Email _____

Payment: ☐ Check ☐ Cash ☐ My gift is enclosed
Charge: ☐ Visa ☐ MC ☐ Disc. ☐ AmEx Credit Card Number _____
CVV Code: _____ Expiration Date _____ Signature _____

In Honor/Memory of _____ Send Acknowledgement to _____
Address _____ City _____ State _____ Zip _____

ALS ASSOCIATION Greater Chicago Chapter

220 W. Huron St., Suite 4003
Chicago, IL 60654

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