

CREATE A WORLD WITHOUT ALS



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



The Story of the Sunflower

"The sunflower 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 impacted by ALS."

-Shirley Hoffman Schmelzle



In 2012, The ALS Association Greater Chicago Chapter adopted the sunflower as the official symbol for ALS Awareness in honor of Shirley Hoffman Schmelzle. Shirley, an individual who lived with ALS, was a retail marketing executive. Shirley's aspiration was to have a symbol evoke a sense of hope, grace and dignity and to reflect the support that those living with ALS receive from their team of supporters.

Share your #SunflowerSightings photos on social media and tag @ALSChicago

DEAR FRIENDS,



One of the most important foundations for any organization is a clearly defined purpose. This year we celebrated our fifteenth year as The ALS Association Greater Chicago Chapter. The chapter was established with the purpose of providing care services, advocating and funding research for the ALS Community.

Since 2004, we have experienced unprecedented growth for the need of our services in our service territory: Central Illinois, Greater Chicagoland, and Northern Illinois. Some of our achievements:

- Expanded care service programs including the Caregiver Bootcamp Program
- Achieved success with strategic advocacy efforts including the doubling of funding for the National Institute of Health (NIH) investment in ALS Research
- Invested in research which has brought about new discoveries
- Surpassed our goals with the Walk Program, the Run to Defeat ALS Program and the ALS Classic

We are privileged to serve our community with purpose and dedication. Enjoy reading about the accomplishments in ALS Care, Advocacy and Research we made happen together. Let's not lose the momentum. Join us with your time, talents, and treasure as we continue the journey together making a major impact for our ALS Community.

Warm Regards,

Julie M. Sharpe
President and CEO, The ALS Association Greater Chicago Chapter



As we approach the end of the Chapter's 15th anniversary year, I can not believe the progress that has been made in the fight against ALS. This does not happen by accident. The dedication of our staff and volunteers is unsurpassed by anything I have ever seen. Also, our donor base and supporters have been so very generous to help us achieve our goal of finding treatments and someday a cure to eradicate this horrible disease.

As I look to the future, I truly believe we all can and will make this happen. Let's make 2020 an even better year.

Thank you all for your past, and continued support. I hope you all have the happiest of holidays and a prosperous and joyful new year.

Sincerely,

Toby Kucharski
Chairman, The ALS Association Greater Chicago Chapter

FIFTEEN YEARS, ONE MISSION

2019 marked The ALS Association Greater Chicago Chapter's fifteenth year serving Northern Illinois, Central Illinois, and Greater Chicagoland. We continue our commitment 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 the past decade and a half there have been many highs and lows: moments of discovery and advancement; ones of sadness and loss; ones of community and connection. Here is just a short list recapping our fifteen years.



15

annual Chicagoland Walks to Defeat ALS, bringing thousands together to unite and fundraise for those living with ALS



14

full, part-time, and contract staff working to meet the needs of those we serve



13

years teeing off The ALS Classic



12

months a year in service to individuals living with ALS and their families



11

disciplines represented at Certified Treatment Centers of Excellence



10

years and running of TeamALS representation in the Bank of America Chicago Marathon



09

years of sharing and learning at the Educational and Scientific Symposium



04

local Walks to Defeat ALS



03

core values: compassion, integrity, urgency



02

Certified Treatment Centers of Excellence



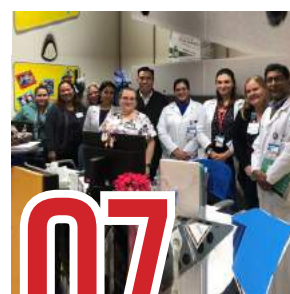
08

support group locations meeting monthly



06

upcoming in-person bereavement programs in 2020



07

ALS Multidisciplinary Clinic partners



05

years since the Ice Bucket Challenge went viral (see page 12 for its lasting impact)



01

vision: create a world without ALS.

CARE SERVICES



For fifteen years, The ALS Association has empowered people affected by ALS by supporting increased access to clinical care and support services. The Greater Chicago Chapter delivers a robust portfolio of care and support programs designed to enhance quality of life, a suite of multidisciplinary clinical programs where diagnosed persons can access expert clinical care, and comprehensive community and professional educational programs offering tools that support families, health care practitioners, and volunteers in the delivery of care and support.

Four Hundred and Eighteen

 individuals living with ALS served in 2019

Made 401 home visits to individuals living with ALS



Completed 572 visits with individuals living with ALS at our multidisciplinary clinics

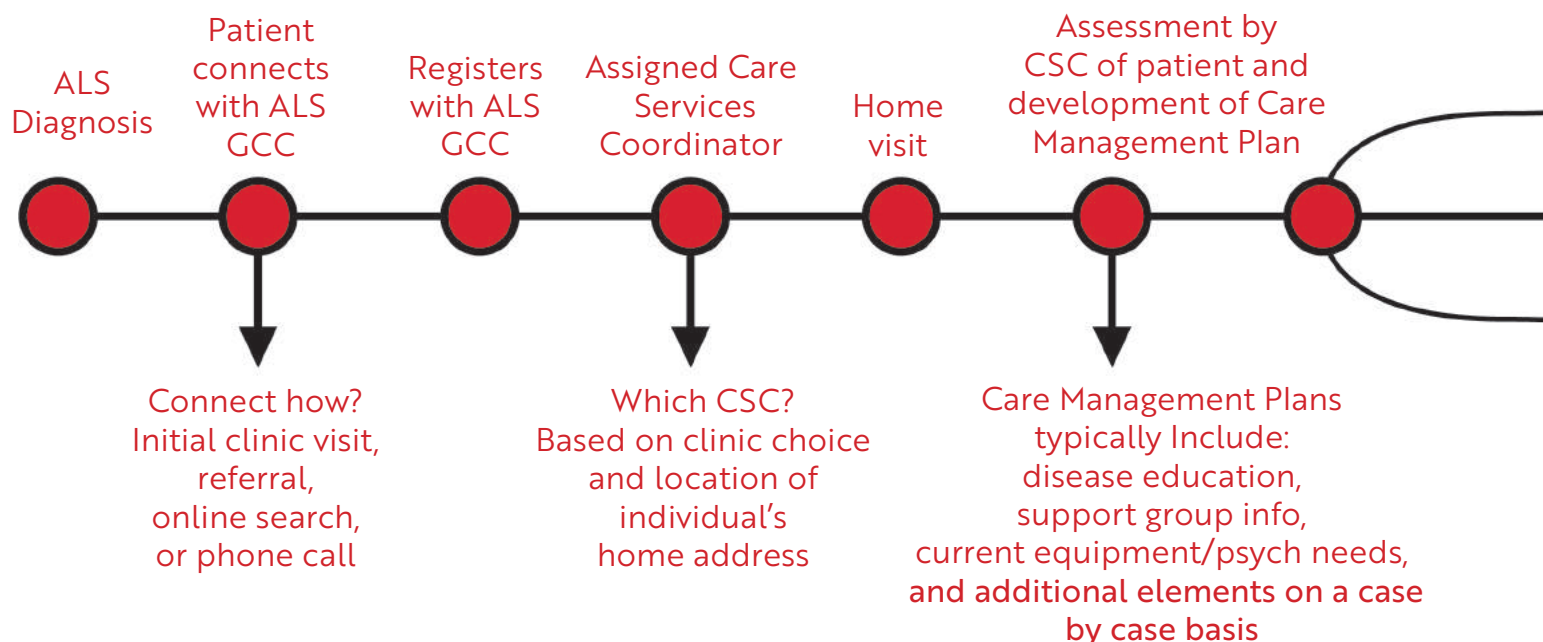


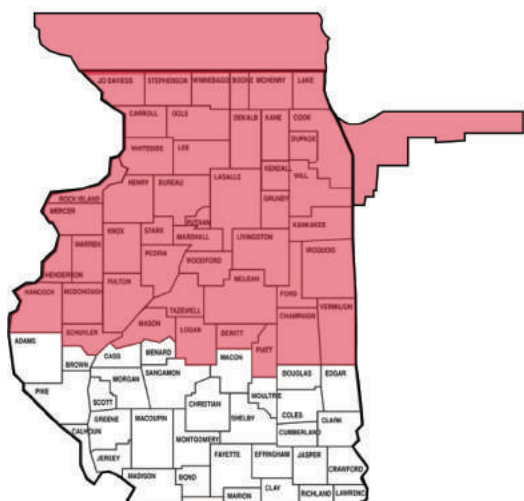
Led 78 support group meetings Attended by 739 individuals



Educated 391 individuals through 17 in-services

Continuum of Care

 with the Greater Chicago Chapter by your side



Service Territory

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

CHAPTER SERVICES

HOME VISIT PROGRAM

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.

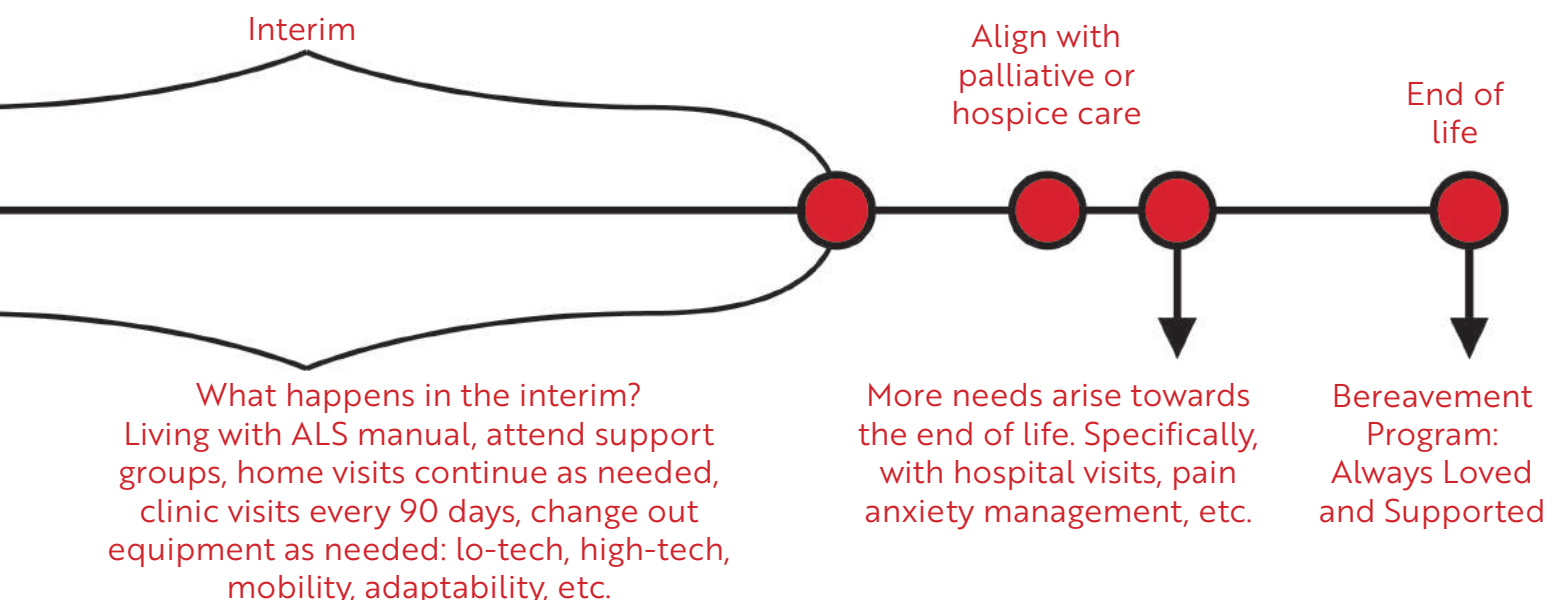
RESPIRE CARE PROGRAM

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.

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.

"The loan of the Liftkar enabled us to stay in our own home, when otherwise we would have had to move to an elevator building." -ALS Family Caregiver



CHAPTER SERVICES (continued)

SUPPORT GROUP PROGRAM

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.

"The monthly support groups had a hugely positive impact on us, enabling us to meet, and become friends, with others in similar circumstances to our own. The opportunity to share our experiences and our concerns allowed us to better navigate the complexities of this unforgiving disease." - ALS Family Caregiver

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 PROGRAM

In 2019, 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.

"It was the best thing I could have done." - ALS Family Caregiver
"Throughout my father's battle with ALS, your organization has helped me and my family be better prepared with information and resources. Thank you for everything you have done and continue to do." - ALS Family Caregiver

PROFESSIONAL IN-SERVICE PRESENTATION PROGRAMS

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.



BEREAVEMENT PROGRAM | ALWAYS LOVED AND SUPPORTED

This is a specialized program to support those who have lost a loved one to ALS. The focus will be on helping those bereaved to cope with their loneliness, how to understand their new roles, and healing ways to manage their emotional pain.



ALS MULTIDISCIPLINARY CLINICS

WHAT IS THE MULTIDISCIPLINARY MODEL?

This clinic model provides high-quality, state-of-the-art ALS care and clinical management along with access to the latest treatments for individuals living with ALS. It brings together physicians including neurologists, pulmonologists and psychiatrists with a team of specialists like physical, occupational and speech therapists, nutritionists, social workers, and palliative care staff. This team of specialists, through this clinic model, always joined by one of the Chapter's Care Services Coordinators, provides comprehensive, specialized, sensitive care that addresses all the needs of individuals living with ALS in one place at one time. Research suggests that patients who receive treatment at an ALS Multidisciplinary Clinic live longer and have a better quality of life.



IN OUR CHAPTER

The ALS Association Greater Chicago Chapter supports six ALS Multidisciplinary Clinics including two Certified Treatment Centers of Excellence. In 2019, there were 572 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.



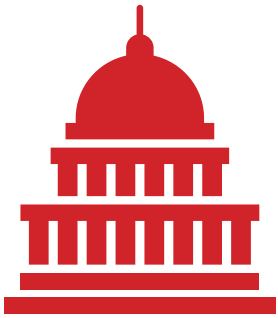
NEW IN 2019

Loyola's ALS multidisciplinary clinic opened in September 2019 with much anticipation and excitement. This clinic is sponsored and supported by The ALS Association Greater Chicago Chapter and will be a great benefit to all of Loyola's ALS patients and patients in the Western suburbs who need advanced multidisciplinary ALS care. The clinic's co-directors are Dr. Lawrence Zeidman, a neurologist, and Dr. Amy Guralnick, a pulmonologist with expertise in treating the breathing difficulties associated with neuromuscular diseases. The clinic features a neurologist, a pulmonologist, a psychologist, and physical, occupational, respiratory, and speech therapy services. Additionally, the clinic provides support services for patients and families. The goal is to improve patients' quality of life using multiple specialists.

The clinic meets once a month and an ALS Association representative is on-site with each clinic to help coordinate and optimize care. Treatment options are discussed at each visit, and all care is coordinated by the various services to make sure patients get their needs met.

For appointments please call Frank Durkalec at 708-216-3123.

ADVOCACY



The ALS Association Public Policy Program empowers advocates to talk about issues important to people living with ALS. Our goal is to educate policymakers and the public, and to drive toward smart decisions about ALS – related research, treatments and access to care.

Federal and state governments play a vital role in ALS research, drug development, and the ability of people with ALS to get the health care they need. Every day, policymakers at all levels of government make decisions that could affect funding for ALS research and programs that serve people living with ALS. Our advocates educate elected officials about the urgent need to find a cure and treatments for ALS through meetings with members of Congress, writing letters, sending emails, and making phone calls. The ALS Association is the largest and most influential national advocacy organization focused solely on ALS.

In addition to year round advocacy, during May, The ALS Association hosts its annual “Day on the Hill” and Public Policy Conference. The Greater Chicago Chapter leads a delegation of individuals living with ALS, caregivers, family members, and volunteers from across our service territory to advocate on behalf of the ALS Community. It is an inspiring experience for those who attend ensuring the voices of the ALS Community are amplified by the nearly 1,000 individuals who descend upon “the Hill”. Results from our efforts have made an indelible impact.

“We were honored to be chosen as advocates for ALS in Washington D.C. We had a great group of people and were able to meet with many Congressmen/women and two Senators who listened to our stories of what it is like to live with this disease. It was a whirlwind four days of seminars, advocacy, fellowship and fun. We are thankful that we were able to make the trip and strive to make a difference for those of us that live with ALS.” -Susan and Jeff Blaha



How The ALS Association and Advocates Successfully Convinced Congress to Preserve and Increase Funding for ALS Research Priorities:

Updated our research report on **"ALS and the Military"** which shows that **all military veterans are nearly twice as likely to develop ALS as civilians**, regardless of branch or era of service.



Enrolled bipartisan congressional champions to lead a concerted campaign behind the scenes in the House and Senate.

\$20 MILLION

Secured the support of **133 representatives and 26 senators** for "Dear Colleague" letters to increase funding for DOD from \$10 to \$20 million and fully fund the National ALS Registry at \$10 million. These letters are critically important because they concretely demonstrate Congressional support.



Supported advocates in meeting with more than **700 members of Congress** at The ALS Association

Chapter Fly-In and National ALS Advocacy Conference. Advocates also conducted many more meetings "back home" in the state or district.

Submitted **60+ individual office appropriations request forms** with every member of Congress on the House and Senate Appropriations Subcommittees on Defense and Labor-HHS-Education regarding the ALSRP and National ALS Registry.



Activated our ALS advocates through multiple email campaigns resulting in more than **13,800 letters** and more than **3,600 tweets** sent to Congress.



Mobilized our **39 chapters** to target members of Congress on the House and Senate Appropriations Subcommittees on Defense to move passive supporters into active champions of the ALSRP increase during the committee markup process.

Submitted testimony to the House and Senate Appropriations Subcommittees on Defense and Labor-HHS-Education regarding the ALSRP and National ALS Registry.



And much more!

It's because of the hard work of ALS advocates from across the country that we've been able to secure this level of funding. Your advocacy continues to make a big difference for our ALS community. Become an Advocate Today!



Sign up for Advocacy Alerts in Just a Few Clicks:
alsa.quorum.us/register

CHALLENGE ME



THE ALS ICE BUCKET CHALLENGE WAS A GLOBAL PHENOMENON THAT RAISED MILLIONS OF DOLLARS AND CHANGED THE FIGHT AGAINST ALS FOREVER.

DONATIONS RAISED THROUGH THE 2014 ALS ICE BUCKET CHALLENGE SPURRED A MASSIVE INCREASE IN THE ALS ASSOCIATION'S CAPACITY TO INVEST IN PROMISING RESEARCH, THE DEVELOPMENT OF ASSISTIVE TECHNOLOGIES, AND INCREASED ACCESS TO CARE AND SERVICES FOR PEOPLE WITH ALS.

5 NEW GENES

discovered since the ALS Ice Bucket Challenge, which will spur new therapies.



\$89 MILLION

committed to research to advance the search for treatments and a cure.



MORE THAN TRIPLED our ALS research budget.

The ALS Association is the largest private funder of research worldwide.



15,000 PEOPLE

per year helped with community-based services through their local ALS Association Chapter.



FIRST EVER

guidance submitted to the FDA to speed the development & approval of new ALS treatments.



EXPANDED

our clinical network to increase availability of ALS care.



11 global research collaborations that have already resulted in 2 new antisense drugs targeting SOD1 and C9orf72 in development.

\$115 MILLION

donated through the ALS Ice Bucket Challenge during an 8 week period in 2014.

MORE THAN 17 MILLION

people uploaded their challenge videos to Facebook.



INVESTED

in technology and innovation to help people with ALS live fuller lives.



THE ALS ICE BUCKET CHALLENGE DIRECTLY IMPACTED THE LIVES OF PEOPLE IN YOUR COMMUNITY:



CLINICAL CARE



ASSISTIVE TECHNOLOGY



SUPPORT GROUPS



MEDICAL EQUIPMENT LOAN



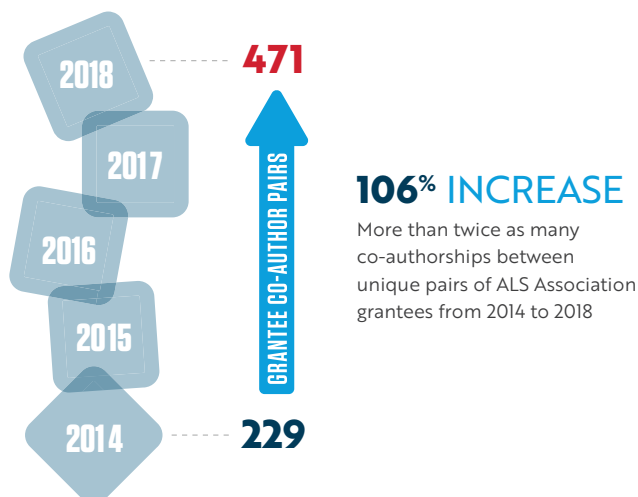
CARE GRANTS



CARE COORDINATION

SHARING KNOWLEDGE from ALS RESEARCH

ALS Association grantees are expanding the reach of their discoveries through collaborations and publications.



How ALS Ice Bucket Challenge donations are helping in the fight against ALS.



SURVEY of ALS RESEARCHERS

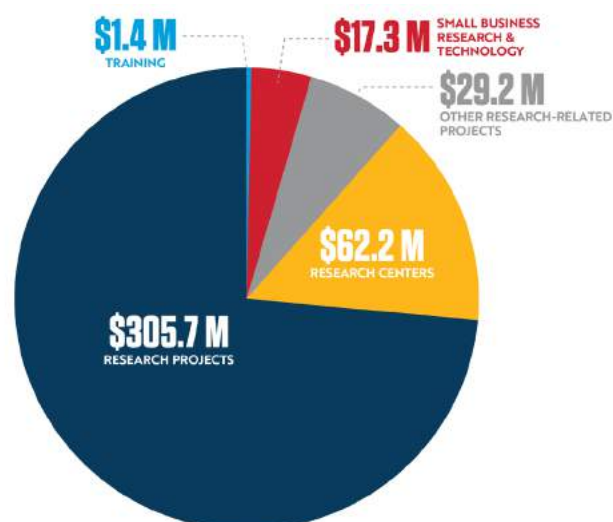
ALS researchers who received grant funding from The ALS Association after the ALS Ice Bucket Challenge shared their accomplishments.

To what extent has receiving a research grant from The ALS Association accelerated your research output?

84% of respondents rated 4 or 5 on a 5-point scale

\$416 MILLION

Invested by the National Institutes of Health (NIH) in ALS Association Grantees from 2014 to 2018





EDUCATIONAL & SCIENTIFIC SYMPOSIUM

Nearly two hundred members of the ALS Community gathered at RUSH University Medical Center for the ninth annual Educational and Scientific Symposium in October. This annual day of learning and community building provides the opportunity for researchers, doctors, individuals living with ALS, caregivers, and family members to hear from one another about developing research and from veteran service providers familiar with ALS challenges and needs.

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 fifteen vendors present representing industries of respiratory care, pharmaceuticals, home health care, mobility and much more.



Save the Date for 2020: Wednesday, October 28



Expert Panel

At the expert panel luncheon, guests heard from four individuals in the ALS Community who provided insight to their area of the ALS world. Spanning topics including research, diagnosis, and advocacy for the ALS Community, attendees heard presentations and were invited to ask questions to the speakers. The panel was lead by Neil Thakur, Ph.D, Executive Vice President for Mission Strategy at The ALS Association who spoke on the advancements made in 2019 by The ALS Association in research, care, and advocacy.



Panelist John Ravits, MD, is the director of the ALS clinic at UC San Diego Health and vice chair of adult neurology and the neurological sciences. Dr. Ravits presented on the growing transformation of ALS research to a more communicative and collaborative community.

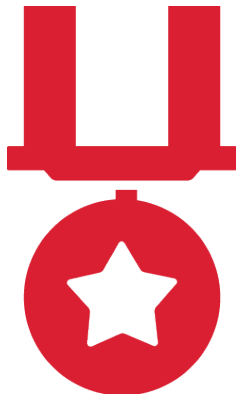
Chris Zallek, MD, is a neuromuscular disorders specialist at the OSF HealthCare Illinois Neurological Institute, Clinical Assistant Professor of Neurology at the University of Illinois College of Medicine – Peoria, and the neuro health investigator at Jump Simulation Center. Dr. Zallek presented on developing tools and technologies to accelerate the diagnosis process and track disease progression.



Michael Robinson, MD, retired from AbbVie in 2016 after being diagnosed with ALS. While at serving as a Vice President of AbbVie, Dr. Robinson lead a team of over 400 scientists and physicians involving therapeutic areas including Neuroscience, Hepatology, Immunology, Oncology, Endocrinology, and Women's Health. Dr. Robinson gave his unique perspective on the isolating nature of ALS an individual living with the disease with a medical background.

Hear the presentations at:
bit.ly/alssymposium2019

ALS IN THE MILITARY



Eighty years ago, baseball legend Lou Gehrig gave his name to a mysterious and rare disease called amyotrophic lateral sclerosis (ALS). He stood on the field at Yankee Stadium on July 4, 1939 and delivered one of the most memorable speeches in American history, announcing to the world that “today I consider myself the luckiest man on the face of this earth.” Lou Gehrig was an American hero.

Today, we know that besides being a hero, Gehrig had something else in common with the men and women who have served and are serving in the armed forces of our country - his disease; ALS.

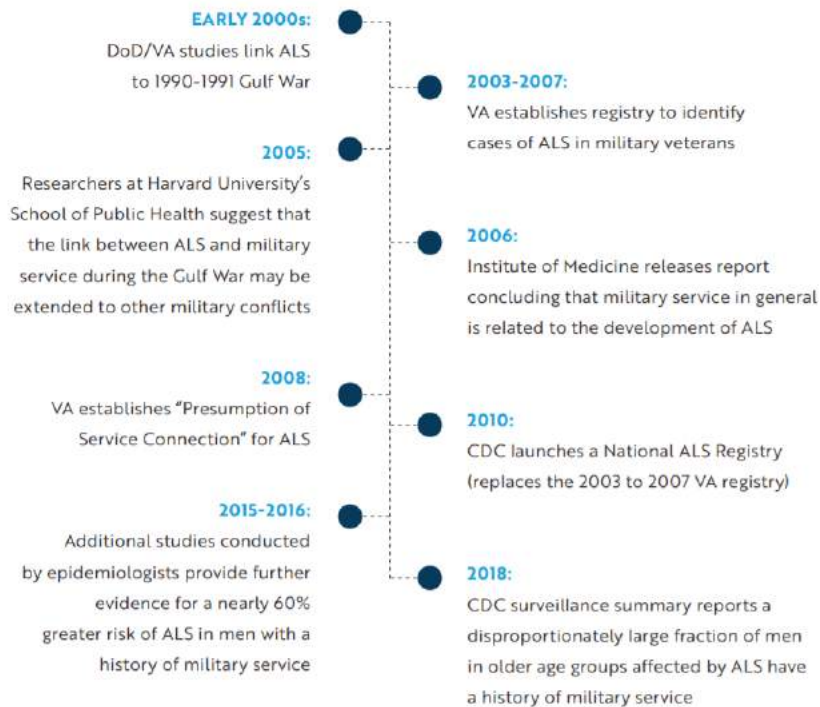
The ALS Association has developed a report, “ALS in the Military: Unexpected Consequences of Military Service,” that details the numerous studies that have been conducted which have found that:

Military veterans, regardless of the branch of service, regardless of the era in which they served, and regardless of whether they served during a time of peace or a time of war, are at a greater risk of dying from ALS than if they had not served in the military.

The full report is available on The ALS Association’s website, www.alsa.org/Military and includes reviews of numerous studies, reports, and other evidence demonstrating the link between ALS and military service:

- Harvard University: Studies conducted in 2005 and 2009 by researchers at Harvard University and funded by the Department of Defense and the National Institutes of Health concluded that all military veterans, regardless of branch or era of service are nearly twice as likely to develop ALS.
- Presumption of Service Connection: In 2008, the VA implemented regulations to establish a presumption of service connection for ALS. Under the regulation, the VA presumes that ALS in military veterans was incurred or aggravated by a veteran’s service in the military. As a result, veterans with ALS and their survivors are eligible for “service connected” benefits.
- Gulf War Studies: Studies conducted by the Department of Defense, Department of Veterans Affairs and University of Texas Southwestern Medical Center found that those who served in the 1991 Persian Gulf War are approximately twice as likely to develop ALS as those who did not serve in the war.

Timeline of Reports Linking ALS to Military Service



• Research Advisory Committee on Gulf War Veterans Illnesses: Congressionally established advisory committee reported that "Gulf War veterans exhibit evidence of neurological problems, including a significant excess in the rate of amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease." The 2008 report stated that "The most serious condition reported to affect Gulf War veterans at a higher than expected rate is amyotrophic lateral sclerosis."

• Institute of Medicine: 2006 publication reviewed existing evidence and reported that "[T]he implication is that military service in general – not confined to exposures specific to the Gulf War – is related to the development of ALS. The findings, if validated in other studies, suggest that exposures during military services, even among those with no wartime service, might be responsible."

• VA ALS Registry/National ALS Registry: The VA established a registry to identify cases of ALS in military veterans. From 2003 to 2007, the registry identified more than 2,100 veterans with ALS and has supplied data vital for ALS research. The National ALS Registry, created by Congress in 2008 at the Centers for Disease Control and Prevention also is collecting data on veterans with ALS and was launched in October 2010.

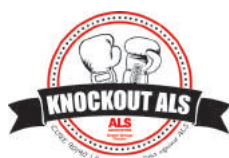
The ALS Association urges Congress to support our heroes in the military, including funding the research that will help us learn why ALS strikes military veterans and how the disease can be treated, prevented and ultimately cured. This is vital, for ALS is among the only specific diseases that occurs at a higher rate in all veterans, regardless of their era of service. Help us fight for our veterans, just as they fought for us.

View the full report: www.alsa.org/Military



SPREAD THE WORD

The ALS Association Greater Chicago Chapter is committed to educating the public about what ALS is, its effect on the families battling it, and what someone can do to become involved in the fight against the disease. We strive to create meaningful awareness campaigns in Illinois and beyond.



Cure 90/90

Every 90 minutes, someone is diagnosed with ALS and every 90 minutes, someone loses their battle to ALS. We kicked off our annual Cure 90/90 day on Daley Plaza, spreading the word about ALS in downtown Chicago. Later in the morning, we

transitioned to the UFC Gym in River North to "knockout ALS" and spread information about the services the Greater Chicago Chapter provides, facts of ALS and the reality of living with the disease. Next up, we hopped on the road to visit businesses participating in the inaugural You Shop, We Give campaign.



You Shop, We Give

From May 18th-25th, participating businesses throughout Chicagoland donated 1% of their sales to The ALS Association Greater Chicago Chapter, I AM ALS, the Muscular Dystrophy Association, and the Les Turner ALS Foundation. Over 50 businesses

in more than 70 locations participated in this inaugural week, and we visited shops participating to thank them for their dedication and to spread the hopeful sunflower ALS symbol.



Iron Horse Rally

Thank you to everyone who took part in our third annual Iron Horse Rally Ride to Defeat ALS. The rain couldn't stop us from embarking on our 60 mile ride spreading awareness and raising funds to fight ALS. Thank you to Lou Malnati's and Nothing

Bundt Cakes for providing food and to the Batavia VFW and Fox River Harley Davidson for hosting us.

May is ALS Awareness Month but you can spread awareness year-round!



Step Up to the Plate

Established in 2011 to provide the opportunity for the baseball community to participate in the fight against ALS, this program is designed to provide a meaningful experience for those that love the game and all it stands for, which is easy to execute for coaches, partners, and sponsors. It allows team members, partners and sponsors to participate in their local communities while helping to build awareness and support in the fight against ALS. In 2019 Step Up to the Plate events took place across the chapter, from high schools to the minor leagues.

Larry's MLB Tour

Larry Falivena was diagnosed with ALS in 2017, and this MLB season he completed one of his personal dreams while generating awareness for ALS nationwide: he visited every MLB ballpark across the country. Along the way, he met with other individuals living with ALS and interviewed them about their lives and battle with the disease. Larry raised over \$30,000 for ALS this year and was interviewed on news stations across the country, including our own WGN. While in Chicago, Larry visited both Wrigley Field and Guaranteed Rate Field. If you'd like to learn more about Larry's travels, visit CHALLENGELARRY.ORG.

Did you know? 2019 marked the 80th anniversary of Lou Gehrig's famous "Luckiest Man" speech.

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.

Over 3,400 participants came together this year for superhero themed Walks in Chicagoland, Peoria, Rockford, and Champaign. The superhero theme brings into reality that we don't need to have superpowers to defeat an enemy...every single person that joins the fight is a superhero in the battle against ALS. Walkers raised over \$883,000 in support those living with ALS in the communities, smashing our overall Walk goal. THANK YOU!



"When I am on stage looking into the crowds, it feels like one giant family...we are all in this together. I am proud of each person that joined us this year...whether it was year one or year twelve, you being present matters! To the individuals living with ALS...we do this for YOU! I hope you feel the love and support surrounding you."

-Kendra, Director of Development



Chicagoland

Cantigny Park, Wheaton, IL
139 Teams | 2,130 Participants | \$602,371 Raised

"These dollars are being used to fund programs that are not covered by insurances. Without this support, most families will have to carry the financial burden or not be able to access these services altogether." -Joumana, Director of Care Services

SAVE THE DATE: Kick-Off: 4/7/2020 | Walk: 6/6/2020



Peoria

Dozer Park, Peoria, IL
33 Teams | 580 Participants | \$155,279 Raised

"Hitting this goal means continuing to provide quality support, equipment, and care to patients of Central Illinois close to home rather than feeling alone in their journey..." -Kellie, Care Services Coordinator, Central IL

SAVE THE DATE: Kick-Off: TBD | Walk: 9/12/2020



Rockford

Rock Valley College, Rockford, IL
36 Teams | 399 Participants | \$78,120 Raised

"It is humbling to see the family and friends of those we have served continue to support us every year by keeping their teams active, or volunteering to make the event the success that it is." -Peggy, Care Services Coordinator, Northern IL

SAVE THE DATE: Kick-Off: TBD | Walk: 9/19/2020



Champaign

Dodds Park, Champaign, IL
17 Teams | 329 Participants | \$47,350 Raised

"The Walk is an opportunity...where for a couple of hours everyone is surrounded by people who truly understand... Everyone gets to be present in whatever they feel, surrounded by the love and support of others ready to give a hug, a laugh, or share a memory." -Kellie, Care Services Coordinator, Central IL

SAVE THE DATE: Kick-Off: 6/22/2020 | Walk: 9/26/2020

RUN TO DEFEAT ALS®



2019 marked the largest TeamALS participation in the Bank of America Chicago Marathon to date, and the largest TeamALS endurance team nationwide. 150 bibs raced through the neighborhoods of Chicago on a brisk October morning, dedicating each step to their ALS heroes.

An incredible \$354,388 was raised by TeamALS, striding past their original goals and blowing past all previous fundraising. Many runners also took to the streets in their TeamALS gear, where roughly 1.7 million spectators cheered them on and saw how important battling ALS is to us.





Top Teams

Team Michelle.....	\$34,687
Sinnott Strong.....	\$29,868
Cortland4ALS.....	\$27,575
Team BEAR.....	\$22,106
DROP KICK ALS.....	\$13,050
SanDiegoGirls.....	\$6,226
#grams4life.....	\$6,090
For Phil Green.....	\$5,200
KC_Run26for26.....	\$4,043
Flo's Girls.....	\$2,580

Top Runners

Ted Collie.....	\$25,475
Angelo Grecco.....	\$20,471
Ja Vandura.....	\$16,930
Luke Jennings.....	\$13,721
Mike Sulentic.....	\$10,665
Wendy Sturges.....	\$9,681
Jack Stoneberg.....	\$9,217
Jody Freije.....	\$8,600
Jane McEnaney.....	\$7,491
Melissa Trafton.....	\$7,359

"It was an amazing, emotional experience. Running for TeamALS made the marathon unlike any other experience and I have run 30+ marathons and many Ultras." -2019 TeamALS Runner

"Running with Team ALS has been a true blessing. After losing my father in March to ALS, training for and running the Chicago Marathon with the support of Sarah and many others was a blessing beyond words. My gratitude is immense and I know my dad is smiling that I was able to be a part of such a wonderful group of people supporting a truly incredible cause." -Mark Greco, 2019 TeamALS Runner



Are you ready to race 26.2 miles toward a cure?

The 2020 Bank of America Chicago Marathon will take place on Sunday, October 11th. If you're ready to join TeamALS please contact sarah@alsachicago.org or visit runtodefeatal.org

TEAM CHALLENGE ALS



Test your strength. Push your limits. Fight ALS. Did you know you can turn any endurance competition into a fundraiser for ALS? Participants combine their passion and commitment to finding a cure for ALS while achieving physical challenges through athletic events, such as marathons, cycling events, winter sports, obstacle course races and other endurance activity. In 2019, The Greater Chicago Chapter ran, climbed, and more toward fighting ALS.



GRAYCOR TOUGH MUDDER: dozens of Graycor employees participated in their fourth Tough Mudder event in Rockford this year, tackling approximately ten miles of rough terrain and more than 20 obstacles that required commitment, team work, and creativity. The #GraycorTough team raised over \$55,000 towards ALS care and research!



DR. FRYER'S FLIERS ran the Chicago Half Marathon, dedicating their 13.1 miles in honor of Dr. Fryer, who was diagnosed with ALS in 2017. They raised over \$12,500!



THE ALS CLASSIC



The 13th annual ALS Classic presented by The Hartford at Cog Hill Golf Course & Country Club was held on Wednesday, September 4, 2019, hosting 168 golfers and raising over \$125,000. It was an outstanding day of golf and fellowship in support of the ALS Community and our mission. We are grateful to The Hartford and all our sponsors including Travelers, Gallagher, Aon, and Hydratight; and all attendees for their support and generosity.



Save the Date for 2020: Wednesday, September 9, 2020

Interested in learning more about sponsorship or participating in The ALS Classic?
Contact Julie at julie@alsachicago.org or 312-932-0000.

TWO FIRSTS FOR THE GREATER CHICAGO CHAPTER

BMW Championship

In 2019, The ALS Association Greater Chicago Chapter was given the opportunity to host a food and beverage tent at the BMW Championship golf tournament. Held in August at Medinah Country Club, volunteers from all areas of our mission stepped up to serve snacks and drinks to happy customers. Thank you to everyone who assisted with this new endeavor -- ambassadors, volunteers from Goldman Sachs, and TeamALS runners! Between receiving a portion of the sales and tips from the event, we raised over \$10,000! We hope to see everyone next year on August 20-23, 2020!



The Chicago Auto Show's First Look for Charity



One of Chicago's most anticipated charity events, First Look for Charity offers food, beverages, entertainment and a preview of the nation's largest auto show. Be among the first to view the spectacular event by attending the black-tie First Look for Charity on February 7, 2020, benefiting 18 nonprofits, including for the first time The ALS Association Greater Chicago Chapter. Top-shelf refreshments complement abundant hors d'oeuvres from notable Chicago eateries, and one attendee will win a brand new vehicle! Tickets are \$275, corporate sponsorships available.

Get your tickets today: bit.ly/firstlookals

TURNING CREATIVITY UP TO 11



DIY fundraisers give you the freedom to use your diverse talents to support our common cause. Do-It-Yourself fundraisers are hosted by passionate individuals or groups that raise funds and awareness for The ALS Association Greater Chicago Chapter. The Chapter provides the tools, and the DIY part lets you hold your event when and where you like, based on your individual interests, schedule, and budget!

There were dozens of amazing DIY Events in 2019. We continue to be amazed by what our supporters come up with and choose to do to benefit the cause.

RACE FOR A CURE (Top Left):

Throughout the year volunteers sold 50/50 raffle tickets at the Byron Dragway to guests attending the races.



OKTOBERFEST (Top Right):

Cheers! Guests enjoyed a night at The Dock in Joliet with delicious food and drinks, plus a stein-holding competition!



HAIR-WARENESS (Bottom Right):

Team members at Uptown Animal Hospital rocked ALS red in their hair as a unique and colorful fundraiser.



POPTIVISM (Bottom Left): 50% of sales from this PopSocket are donated to the Chapter! Get yours at Poptivism.com by looking up our charity by name.



Ready to Do-It-Yourself? We can't wait!

Contact Sam at samantha@alsachicago.org or 312-932-0000.

LEND A HAND



Corporate Volunteer Days

IMPACT Day is a year-round celebration of Deloitte's commitment to local communities. The Chicago office hosted IMPACT Day activities this June and Deloitte professionals spent the day volunteering for several causes, including The ALS Association Greater Chicago Chapter. We were delighted to be welcomed back and our amazing volunteers helped with projects big and small that played a role throughout our Chapter's work this year.



Day of Giving

Students at Aptakisic Junior High School spent their Day of Giving on December 3rd volunteering for several organizations including The ALS Association Greater Chicago Chapter. Students packed and prepared one hundred handmade quilts to be sent to individuals living with ALS throughout the Chapter territory.



Challenging Youth to Join the Fight

The ALS Association launched a campaign in 2019 to engage kids and teenagers in the fight against ALS, issuing the ALS Youth Challenge and celebrating the first-ever ALS Youth Action Day. On May 19, 2020, Chapters across the country will partner with youth organizations in their communities to identify future activists and philanthropists who will help to defeat ALS by accepting the ALS Youth Challenge. This is a day where kids can set aside time to take the ALS Youth Challenge, raise money and awareness for the fight against ALS, and spread the word.



Join the fun: alsyouthchallenge.org

LEAD THE CHARGE



LOU'S CREW

Our Lou's Crew team of volunteers expands our reach and progress towards our mission. The crew includes students looking to get involved in their community, those who have been personally impacted by ALS and want to make a positive difference in honor of their loved ones, and employee groups who are choosing to come together and use their resources for good. Each

member is extremely valued, and we are grateful for their continued support and commitment. 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. In 2019, Lou's Crew volunteers donated over 3,381 hours of their time and talents to help in the fight against ALS. We are amazed by their generosity and dedication to help in the fight!

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 37 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.

FAMILY ASSISTANCE VOLUNTEER PROGRAM

Living with ALS makes daily tasks more challenging. The Family Assistance Volunteer Program matches trained volunteers with families affected by ALS. Volunteers can help a person living with ALS or their family with anything they might need assistance with, outside of direct care and transportation. By volunteering for a family affected by ALS, you will decrease stress, increase the quality of life for the person living with ALS, and make life a little easier for the whole family.

EXPLORE ALL VOLUNTEER OPPORTUNITIES:

bit.ly/ALSChicagoVolunteer



YOUR TEAM



Julie M. Sharpe
President and CEO
2006 - Present
julie@alsachicago.org



Joumana Baroody, RN, BSN
Director of Care Services
2010 - Present
joumana@alsachicago.org



Kendra Albers
Director of Development
2015 - Present
kendra@alsachicago.org



Peggy O'Connor, RN, BSN
Care Services Coordinator
2015 - Present
peggy@alsachicago.org



Sarah Brandt
Volunteer Coordinator
Run to Defeat Program Coordinator
2012 - Present
sarah@alsachicago.org



Audrey Scafidi, LPN
Care Services Coordinator
2014 - Present
audrey@alsachicago.org



Samantha Courter
Fundraising and Marketing
Coordinator
2019 - Present
samantha@alsachicago.org



Kellie Branch-Dircks, MSW, LCSW
Care Services Coordinator
2014 - Present
kellie@alsachicago.org



Jessica Leeseberg
Administrative Coordinator
2019 - Present
jessica@alsachicago.org



Gema Ramos, RN
Care Services Coordinator
2016 - Present
gema@alsachicago.org



Jennifer Beckman, LCSW
Care Services Coordinator
Social Worker
2018 - Present
jennifer@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



220 W Huron Street Suite 4003
Chicago, IL 60654
312.932.0000
alsachicago.org

THE IMPACT OF YOUR SUPPORT

Make a commitment to yourself and to the ALS Community

Over the years, monies raised have allowed the Greater Chicago Chapter to:

- Expand the Greater Chicago Chapter Care Service Team by hiring Coordinators: RN's, BSN, LPN, MSW, and LCSW who develop individualized care management plans providing guidance to support diagnosed persons and families
- Design and host Caregiver Boot Camps to provide education about the role of a Caregiver, how to use medical equipment and provide an opportunity to ask questions to be better prepared
- Fund 7 ALS Multidisciplinary Clinics, which research has proven results in higher quality of life than more fragmented, traditional patient care
- Broaden the adaptive equipment lending program to include four locations which serve all of our service areas

The ALS Association Greater Chicago Chapter is able fund research, advocate on behalf of and provide these services and programs to individuals living with ALS at no cost because of the support from the ALS Community. We are grateful for your generosity and will continue to strive to have an impact in the lives of those affected by ALS. There are many opportunities to invest with the Greater Chicago Chapter to make a significant contribution to our mission. To discuss these options, contact Julie Sharpe, President and CEO, at 312-932-0000 or julie@alsachicago.org.

CONSIDER A PLANNED GIFT TO THE ALS ASSOCIATION GREATER CHICAGO CHAPTER

In recent years, donors have informed us of their intention to include a gift to The ALS Association Greater Chicago Chapter in their wills. These gifts may provide an estate tax deduction and definitely have a tremendous impact on our ability to provide essential care services while investing in a cure. If you would like information on how to include The ALS Association Greater Chicago Chapter in your will or estate plan, please contact Julie Sharpe at 312-932-0000 or julie@alsachicago.org.

OPERATION SUNFLOWER: RECURRING GIFT PROGRAM

Join the brigade of Operation Sunflower with a monthly donation to The ALS Association Greater Chicago Chapter. Your gift will provide year-round support for individuals living with ALS in Northern Illinois, Greater Chicagoland, and Central Illinois. Signing up for a recurring gift helps The ALS Association Greater Chicago Chapter by providing steady, reliable funding for care service programs, advocacy efforts, and research. To learn more, please contact Kendra Albers at kendra@alsachicago.org or at 312-932-0000.



220 W Huron Street Suite 4003
Chicago, IL 60654

SAVE THE DATES FOR 2020



Don't miss The ALS Association Greater Chicago Chapter's inaugural partnership with:
THE CHICAGO AUTO SHOW'S FIRST LOOK FOR CHARITY
Friday, February 7, 2020 | Get your tickets today at bit.ly/firstlookals



Chicago Walk to Defeat ALS
June 6, 2020

Peoria Walk to Defeat ALS
September 12, 2020

Rockford Walk to Defeat ALS
September 19, 2020

Champaign Walk to Defeat ALS
September 26, 2020



The ALS Classic
September 9, 2020



Bank of America
Chicago Marathon
October 11, 2020



Educational & Scientific
Symposium
October 28, 2020

Stay in the loop: follow us on Facebook, Instagram, and Twitter at [@ALSChicago](https://www.instagram.com/ALSChicago)