



# THE IMPACT OF YOUR GIVING

AN ANNUAL REVIEW OF OUR ADVANCEMENTS IN 2023

2023 marked substantial advancements on multiple fronts. Collectively, we continue to make significant strides in combating ALS while this transformative year saw a pivotal moment in our organizational history. We not only rebranded from ALS Association Greater New York Chapter to ALS United Greater New York but also joined forces with 14 affiliated non-profit organizations to establish ALS United — an innovative membership organization dedicated to those living with ALS and their families across the country.

Throughout the pages of this impact report, you'll learn about our dedicated team providing seamless care, our **Home Visit Program expanding by over 20%** and the Family Grant Program, covering in-home health care and accessibility upgrades, **growing by 33%**. Additionally, our steadfast commitment to state and federal advocacy resulted in an **additional \$500,000 in the New Jersey State Budget**, reaching \$1.5 million.

ALS United Greater New York remains committed to advancing groundbreaking ALS research, **investing over \$16.5 million** in the past two decades, including funding for impactful projects based in New York. We are continuing to expand this support as we partner with academia, industry, nonprofits, and government.

Our transformation is more than a name change; it signifies an evolution for our organization. It represents an exciting future, building upon our decades-long legacy as a trusted resource and re-emerging as one of the largest, local ALS patient service organizations in the nation. We are thankful for your support during this journey and look forward to all we will do together in the coming year!



## 2023 HIGHLIGHTS



CARE SERVICES



ADVOCACY



RESEARCH



FUNDRAISING

## CARE SERVICES

In 2023, we continued our hybrid programs and services while also expanding our offerings. We are now providing in-person home visits on a more regular basis and our families benefit from the wider variety of options to connect with our team. Additionally, we continue to expand our grant offerings and our ongoing continuity of care to approximately 1,000 patients, making 2023 a productive year!

### EDUCATION SUMMIT

Approximately 300 people attended our third annual virtual **Education and Resource Summit** as part of ALS Awareness Month. Among the many educational sessions offered to our community were topics such as Drug Therapies, Genetics, and sessions for Caregivers in English and Spanish. We were proud to conclude the Summit with a screening of the film, “Matter of Mind: My ALS,” a sensitive and realistic portrayal of three individuals living with ALS and their different approaches to living with the disease. One of the film subjects is from our region and she joined for a post-screening discussion.



### EQUIPMENT LOANS

Our Equipment Loan and Assistive Technology programs have enjoyed a great boost this year with the addition of new staff members. Our new ELP Coordinator, Aaron Young, has brought the program to new levels of success by streamlining our tracking and shipping process, enabling us to provide a combined total of 1,158 durable medical equipment pieces and augmentative communication devices in 2023. We continue to provide equipment and devices of all sizes to families in need, and as always this service is free of charge, including delivery. Additionally, Tejal Parikh is our new Accessibility Specialist and, together with Ben Lieman, our Assistive Technology Specialist, has almost doubled the rate of home access assessments being provided.



### MULTIDISCIPLINARY CLINICS

ALS United Greater New York is proud to support ten multidisciplinary ALS clinic programs. Together with our clinic partners and dedicated Care Services staff, we work to meet the needs of the entire ALS community. This past year we welcomed new research clinicians, neurologists, and team members at several of our clinics. We are extremely proud to be nurturing these partnerships with medical professionals. With our robust teams, research opportunities have expanded as well as clinic capacity.



## TEAM SPOTLIGHT

ALS United Greater New York’s Care Service Team has some of the most caring and experienced local staff working with those living with ALS in the Greater New York region. Our local teams have a combined 130 years of experience with our organization. Social workers, nurses, and accessibility/technology specialists who make up our team are locally based around Southern New York and Northern and Central New Jersey. Pictured below are just a few members from our amazing network of professionals.

As a social worker with over 26 years of experience, **Michelle McKenzie, LMSW**, has served as the **Care Services Coordinator** in NYC for the last eight years. During that time, she has encountered incredible individuals facing one of the most challenging experiences of their lives. She understands the immense challenge that comes with receiving a diagnosis of ALS, both for the patients and their loved ones. Often asked by many “How can you continue to do what you do?” she responds, “I feel that I can make a difference.” Leveraging her extensive knowledge of the disease, Michelle not only offers counseling to help individuals cope with the emotional impact of a fatal diagnosis, but she also provides support through bereavement groups. Michelle finds profound meaning in facilitating these groups, creating a nurturing space for families to grieve collectively.



**Nancy Brenner, LCSW**, has been part of our team for over nine years, serving as the **Care Services Coordinator** for Hudson Valley. She not only helps those living with ALS navigate their disease, but she is also an expert in navigating the many systems that they encounter daily. One of these challenges is the Department of Social Security, which can be very complex. Nancy recently helped someone with ALS who had received incorrect information from the Social Security Administration. Thanks to Nancy’s expertise, the issue was resolved, ensuring the person received full coverage and a Medicare supplement.

Our team of advocates, working with lawmakers, helped pass legislation that grants those living with ALS fast-track approval for disability benefits which allowed Teresa, who is living with ALS, to stop working and concentrate on her health. “I walked away from a 30-year career and never looked back. ALS United has become my community,” she said. During a recent home visit, **Kayvan Freeman, RN and Care Services Coordinator** for NYC, surprised Teresa with a beautiful handmade quilt.



Some of the ALS United Greater New York Care Service Coordinators and Technology Specialists at the Lou Gehrig Legacy Gala: Pictured Left to Right: **Ben Lieman, ATP; Tajal Parikh, Accessibility Specialist; Michelle McKenzie, LMSW; Kayvan Freeman, RN; Eileen Margenat, RN; Nancy Brenner, LCSW; Mary Ann Mertz, RN; Debbie Schlossberg, MA, LMSW; Charisse Santos, LPN; and Aaron Young, Equipment Loan Coordinator.**

# ADVOCACY

ALS United Greater New York advocacy works to improve the lives of those living with ALS through legislative measures at both the congressional and state levels.

## CONGRESSIONAL ADVOCACY

In April and August of 2023, we worked to increase federal funding of ALS research for treatments and cures by meeting with members of Congress on video conference. People from our community participated in over a dozen meetings with Congressional members and their staff to advocate for the increase of ALS research funding.

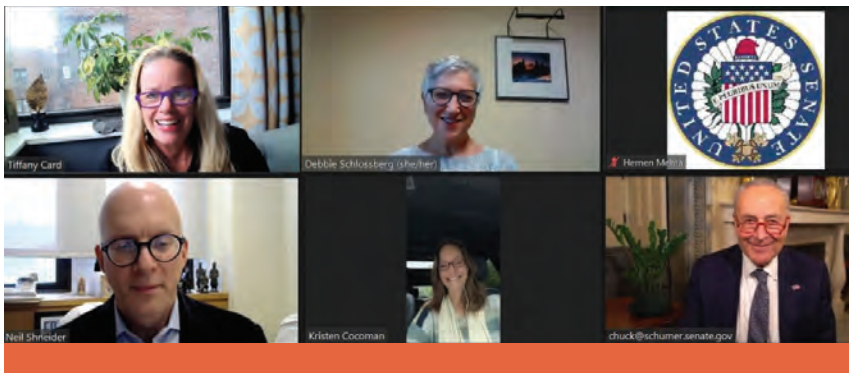
## STATE ADVOCACY

State legislation can help improve the quality of life of those living with ALS. That is why we supported New York's bill which would require a review of rules when establishing a step therapy protocol. We also supported New York's legislation which would prohibit discriminatory coverage and pricing decisions based on genetic testing in life, accident, health, disability, long term care, or medical indemnity insurance. We are also encouraged by the new legislation that provides for patient prescription pricing transparency that was signed by the Governor in March of 2023.

## STATE FUNDING

ALS United Greater New York continues to receive funding by both New York and New Jersey state budgets annually. Thanks to the testimony of a New Jersey resident living with ALS, our New Jersey funding grew to **\$1.5 million dollars**. This funding allowed us to:

- Expand outreach to ALS Community
- Grow Equipment Loan Program
- Increase Family & Patient Grant Program
- Develop our Home Accessibility Program



**Over the last few decades, significant advancements in ALS research have provided valuable insights into the nature and origins of ALS. In that time ALS United Greater New York, formerly The ALS Association Greater New York Chapter, allocated \$16.5 Million to support and expedite the discovery of treatments and a cure for ALS.**

ALS United Greater New York will continue building on this historical support as we seek innovative ways to partner with academia, industry, nonprofits, and government. Our strategic partnerships will amplify the impact of our research investments, hasten innovative idea development, promote collaboration, and propel us forward more efficiently.

Our investments thus far have proven instrumental to many research initiatives with a portfolio that includes support of many notable programs such as the New York Genome Center and The Milton Safenowitz Postdoctoral Fellowship Program. Our most recent list of investments in 2023 include the following programs:

■ **ALS Expanded Access Programs at Columbia University, Eleanor and Lou Gehrig Als Center**

Through Expanded Access Programs (EAPs) approved by the US Food and Drug Administration (FDA), and the Columbia University Institutional Review Board (IRB), our investment will help provide access to promising, investigational therapeutics to ALS patients with limited treatment options.

■ **Prevent ALS, Columbia University**

For those with familial ALS, defining the earliest stage and identifying ALS gene carriers of the disease is key. Over the last six years the DIALS study led by Drs. Mark Garret and James D. Berry (Massachusetts General Hospital) and Dr. Timothy Miller (Washington University in St. Louis) and the ALS Families study led by Drs. Neil Shneider and Matt Harms (Columbia University) have been building a large cohort of presymptomatic ALS gene mutations carriers. DIALS and Families have combined efforts to launch “PREVENT ALS,” a unified presymptomatic cohort with shared methods, shared infrastructure and plans to expand to other sites.

■ **The Milton Safenowitz Postdoctoral Fellowship Program**

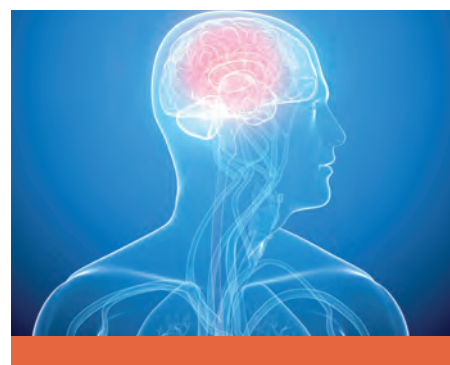
The Milton Safenowitz Postdoctoral Fellowship Program - These ALS Research awards are designed to encourage and facilitate young scientists to enter the field of ALS Research. The program was founded by the Safenowitz family, through Greater New York, and awards are given in memory of Milton Safenowitz. Fellows work with a senior mentor and receive extensive exposure to the ALS research community. The Safenowitz family has been an integral part of our family for over 22 years.

■ **ALS Research Network**

A collaborative research initiative focused on innovative ways to advance promising projects that accelerate translational research & therapy development.

■ **Target ALS: Springboard Fellowship Program**

Target ALS is a non-profit foundation working to accelerate ALS drug and biomarker development. Through our investment in the Target ALS Springboard Fellowship Program, we are supporting a senior lab fellow to transition to an independent academic tenure track.



## EVENTS

ALS United Greater New York brings the ALS community together through various events throughout the year to raise awareness and funds to benefit our mission.

### WALK ALS

In 2023, we held Walk events in New York City, Westchester, Northern New Jersey, Long Island, Jersey Shore, and Hudson Valley. We had more than 4,500 walkers and 470 teams join us throughout the spring and fall to raise awareness and funds in support of the local ALS community. **Make sure to register for one of our six walks in 2024 at [alswalks.org](https://alswalks.org)!**



### THANK YOU TO OUR TOP TEN FUNDRAISING TEAMS!

FOR THE LOVE OF JEMMA

TEAM BETTINA

TEAM YORKTEL

BEHANSTRONG

KATZ WALKERS

TEAM MIKE LEIDERMAN

PABLO'S PALS

TEAM JAY

OUR LOVE FOR MONA

WIN THE FIGHT



### THE ALS IRON HORSE GOLF CLASSIC

More than 100 golfers joined us for the sixth annual outing on Monday, August 21, 2023, at Sands Point Golf Club in Sands Point, NY. The golfers enjoyed a great day on the course and helped raise over \$130,000 for our programs and services.

**Save the date for the Seventh Annual ALS Iron Horse Golf Classic on August 12, 2024.**

## THE LOU GEHRIG LEGACY GALA

The Lou Gehrig Legacy Gala was held at Pier Sixty on Monday, November 6th. This year's program celebrated the progress of ALS research and the evolution of the ways in which we care for those living with ALS. We also announced the transition of our organization to our new brand, ALS United Greater New York, unveiling our striking new logo, setting the stage for a memorable evening.

Under the guidance of Master of Ceremonies **Jeremy Schaap**, and special guest, **Bob Costas**, the event highlighted the presentation of prestigious awards, recognizing exceptional contributions to the ALS community. The 2023 Jacob K. Javits Lifetime Achievement Award was presented to **Mitsubishi Tanabe Pharma America**, for their groundbreaking work to bring forward a treatment for the ALS community and pave the way for future therapies. Our Lou Gehrig Sports Award was presented to **Todd Zeile**, a baseball legend who played for 16 seasons in the MLB. We proudly honored **Jeffrey H. Loria**, a long-time Gala Co-Chair and supporter of ALS United Greater New York with the Champion Award.

The remarkable women of **Her ALS Story** were honored with the esteemed Iron Horse Award for their collective strength and advocacy. Accepting the award on behalf of the group were Leah Stavenhagen, Desi Kessler, Ashley Rivera, and Kaitlin Gonzales. This recognition followed the touching video created by BBDO celebrating the network, which comprises over 100 inspiring women from across the United States and beyond. Initiated in April 2021 by Leah Stavenhagen, **Her ALS Story** emerged from a need for representation among young women who were diagnosed with ALS before the age 35, evolving from a group of twelve members to a thriving community rewriting the narrative of ALS. Through their unity and determination, these women offer hope and empowerment to others facing similar challenges.



**MARK YOUR CALENDAR FOR THE 2024 GALA**  
Tuesday, November 12, 2024, at Pier Sixty in New York City

## LOU GEHRIG DAY

The ALS community and Major League Baseball hit a homerun at the celebration of the third annual Lou Gehrig Day. In stadiums across the nation, teams offered people living with ALS and their families special game day experiences. ALS United Greater New York celebrated the legacy of Lou Gehrig with both the New York Mets and New York Yankees. We were joined by many friends and family at Citi Field on Friday, June 2nd for Lou Gehrig Day. On Tuesday, July 4th, friends joined us at the New York Yankees game to celebrate ALS Day and honor the legacy of Lou Gehrig on the 84th anniversary of his “Luckiest Man” speech.



## TEAM ALS

Over the course of 2023, Team ALS raised more than \$400,000, thanks to the efforts of 93 athletes participating in the TCS New York City Marathon, United Airlines NYC Half, TD Five Boro Bike Tour, the NYC Triathlon, and individual endurance events. We are actively recruiting participants to join our 2024 Team ALS events.

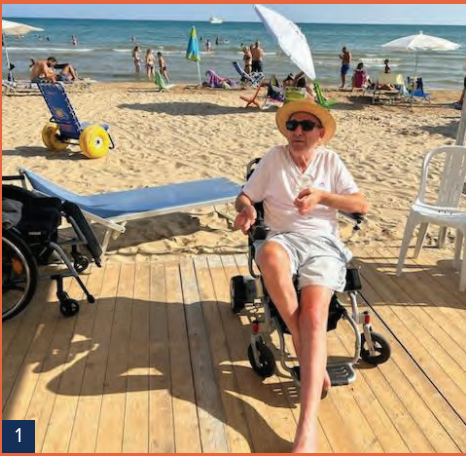


## COMMUNITY FUNDRAISERS

Working with our local community to host their own fundraising events, many participants and volunteers raised ALS awareness and generated more than \$360,000 in donations to support care services, advocacy, and research. Our top fundraisers included the annual **Iron Horse Party**, several golf outings, pickleball games, and a hockey tournament.



## COMMUNITY SPOTLIGHT



1 | **Franco Rosella** was able to visit his birthplace in Italy with the assistance of ALS United Greater New York's Care Team. He needed a special chair to make travel comfortable and manageable. Our team's efforts paid off, and they managed to locate a generous person in Italy with ALS who willingly donated their chair to the Rosellas.

2 | **Dr. Treidler** and **Jay Epstein** pictured at the Christopher Pendergast ALS Center of Excellence at Stony Brook University Hospital. "Had my second clinic and can't say enough good things about the Care Team there. A year and a half into this awful disease; we can't say enough about the support we get from ALS United Greater New York" – Jay Epstein

3 | These young philanthropic entrepreneurs raised awareness about ALS by selling lemonade and bracelets while raising money for ALS United Greater New York.

4 | **Randel McCoy** and **Brianna LaFontaine**, of Long Island were honored by the Members of the Town Board of the Town of Huntington, NY for playing a pivotal role in both fundraising and raising awareness around ALS.

5 | **Sandy Edleman**, accompanied by **Dorothy**, **Aidan**, and **Sage** enjoyed a special night with the New York Knicks arranged by **Melissa Braxton**, Care Services Coordinator for New Jersey.

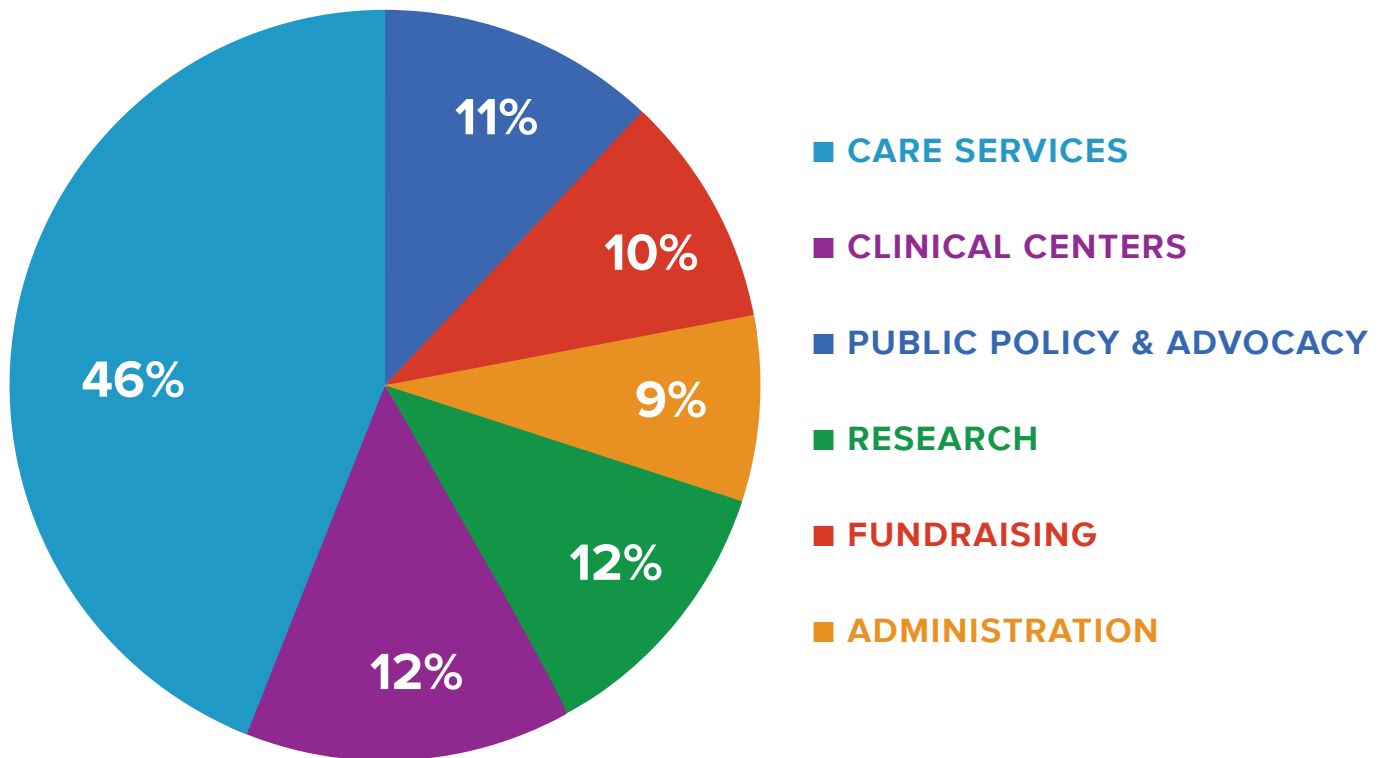
6 | **Tom Long**, with daughter **Alison** and granddaughter **Evelyn** in his ALS United Greater New York loaner power wheelchair on the ramp that was installed with assistance from our Family Grant Program.

7 | ALS United Greater New York provides holiday meals to families currently living with ALS to assist in creating a memorable day. Thanks to the support of our amazing partners at **Citarella** and **Patrizia's**, we were able to provide meals for more than 45 families this holiday season. We are so grateful to **Citarella** and **Patrizia's** for their commitment to making a difference in the lives of people living with ALS and their families.

## FUNDRAISING

The 2023 fiscal year ending January 31, 2024, brought in **\$6.1 million** across all fundraising, including events, major gifts from individuals, foundation grants, and bequests. The dedicated support from donors at every level collectively makes a significant difference throughout the Greater New York ALS community. This impact enhances our vital programs to best serve people living with ALS and their families.

### WHERE ARE YOUR DONATIONS GOING?



**1,268** people living with ALS served

**1,486** people attended **142** support groups

**908** patients received care and clinical management of ALS through one of our **10** multidisciplinary centers

**1,016** home visits were conducted

**1,158** pieces of durable medical equipment and/or communication devices loaned free of charge.

**214** rides were provided free of charge for patients to attend appointments at one of our multidisciplinary clinics.

**\$320,000** in monetary grants to cover in-home health care, home accessibility upgrades, and additional expenses such as prescription co-pays, and more.

ALS United Greater New York is proud to be a part of a very select group of high-performing charities that have earned a Four-Star rating from Charity Navigator, America's largest independent charity evaluator. In 2023, we earned our tenth consecutive 4-star rating from Charity Navigator. That means we have a proven track record of being accountable, transparent, and fiscally responsible, further validating that our supporters can trust our commitment to good governance and financial health.

# PLEASE JOIN US IN THANKING OUR TOP DONORS OF 2023

Andrew Abramsky	Alan and Penny Griffith	Domenick Muro
John Albuerne Family Foundation, Inc.	Jane W. Griffith	National Mah Jongg League Foundation, Inc.
Joseph Alexander Foundation	Alan and Susan Hammer	The William and Anita Newman Foundation
ALS Ride For Life, Inc.	Mary and Kathleen Harriman Foundation	New Jersey State Department of Health
Amylyx Pharmaceuticals	Mary W. Harriman Foundation	New York State Department of Health
Evelyn H. Anderson	Maryann Ingenito	New York Yankees Foundation
Anonymous	Helen Hoffritz Charitable Trust	Jacqueline Nieman
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Bargold Storage Systems	Hospital for Special Surgery	NuMotion
BEB Capital	The Marian B. and Jacob K. Javits Foundation	Old Westbury Golf & Country Club Foundation
Eric and Jen Berniker	Amanda and Daniel Kaplan	Park Pictures
The Birk's Works Foundation, Inc.	The Deana and Sheldon Katz Fund	David Pelton
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The Gluck Family Foundation	Marianne L. Muise	David and Lynette Zinberg
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Thank you to everyone who contributed to the mission of ALS United Greater New York in 2023! Without your support, our programs and services would not otherwise be possible. For more information on how you can expand your mission-based giving through various mechanisms, such as estate planning, IRA rollovers, or gifts of stock and securities, please contact:

**Vivian Banks, Director of Individual and Institutional Giving**

**212-720-3051 and [vbanks@als-ny.org](mailto:vbanks@als-ny.org)**

## 2024 EVENTS

### SUNDAY, MARCH 17

United Airlines NYC Half Marathon

### SATURDAY, MAY 4

Walk ALS New York City  
South Street Seaport  
Pier 16, NYC

### SUNDAY, MAY 5

TD Bank Five Boro Bike Tour

### MAY 16 – 17

Education and Resource Summit

### SATURDAY, JUNE 1

Walk ALS Westchester  
Manhattanville College  
Purchase, NY

### SUNDAY, JUNE 2

Lou Gehrig Day  
Throughout Major League Baseball

### SUNDAY, JUNE 9

Walk ALS North New Jersey  
Saddle River County Park  
Saddle Brook, NJ

### MONDAY, AUGUST 12

ALS Iron Horse Golf Classic  
Sands Point, NY

### SATURDAY, SEPTEMBER 14

Walk ALS Jersey Shore  
Long Branch, NJ

### SATURDAY, SEPTEMBER 21

Walk ALS Long Island  
Eisenhower Park  
East Meadow, NY

### SUNDAY, OCTOBER 20

Walk ALS Hudson Valley  
Walkway Over the Hudson  
Highland, NY

### SUNDAY, NOVEMBER 3

TCS New York City Marathon

### TUESDAY, NOVEMBER 12

The Lou Gehrig Legacy Gala  
Pier Sixty, NYC

## OUR MISSION

Our Mission is to support and empower the ALS community through a collaborative approach to fostering bold research initiatives, advancing national and state advocacy, and providing comprehensive care and support to individuals and families affected by ALS.

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