

## AN ANNUAL REVIEW OF OUR ADVANCEMENTS IN 2024

**A**s 2025 begins, we reflect back on a remarkable year of achievements within the ALS United Greater New York community. Together, we've advanced research, supported families, raised awareness, and amplified the voices of those living with ALS.

2024 began with a historic victory as New York Governor Kathy Hochul secured \$25 million in the New York State budget for ALS research and other neurodegenerative diseases, treatment, and vital services. Care Services continued to evolve as a cornerstone of our work, with highlights including the 4th Annual Virtual Education and Resource Summit, Hudson Valley Patient and Family Day, and the launch of "Conversations With...", a video series exploring the deeply personal experiences of ALS. We also introduced the Joseph Cotrone Holiday Dinner Program to bring joy to families during the holiday season.



Members of the ALS United Greater New York Team

Our Walk ALS season kicked off in March at Madison Square Garden and continued with six regional Walks, raising \$1.5 million. Advocacy efforts produced the passage of the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act. New research partnerships were formed with organizations like Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS) and The Accelerating Medicines Partnership® in Amyotrophic Lateral Sclerosis (AMP® ALS).

ALS awareness shone brightly through events like Lou Gehrig Day at three New York ballparks and three events celebrating the 10th anniversary of the Ice Bucket Challenge, including ringing the opening bell at NASDAQ. Our endurance and fundraising events, including the TCS New York City Marathon, United Airlines NYC Half Marathon, TD Five Boro Bike Tour, and ALS Iron Horse Golf Classic, raised over \$550,000.

The year concluded with the Lou Gehrig Legacy Gala, where New York Governor Kathy Hochul presented our Jacob K. Javits Lifetime Achievement Award to Dan Doctoroff, founder of Target ALS and former NYC Deputy Mayor. The evening also celebrated Board Member David Lubars, and three sports legends: Adam Graves, Thomas Morstead, and John Sterling. Their contributions, alongside your support, have brought us closer to a world without ALS.

**Thank you for being part of this journey. Together, we're making a lasting impact on the ALS community.**

### 2024 HIGHLIGHTS



CARE SERVICES



RESEARCH



ADVOCACY



FUNDRAISING OUTCOMES

# CARE SERVICES

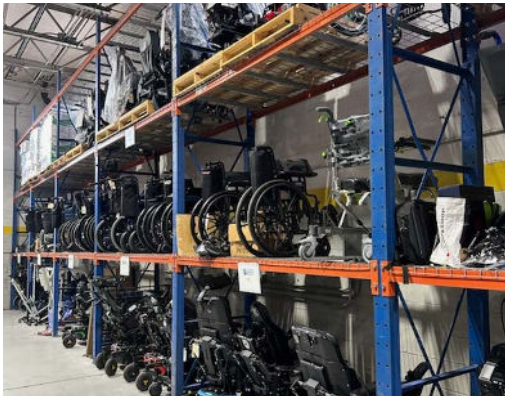
For more than 30 years, ALS United Greater New York has been the region's leading provider of ALS services. Backed by a team with over 192 years of combined experience, we deliver expert, compassionate care through our dedicated staff and clinic partners, supporting patients and families across New York and New Jersey.



Your Greater New York Care Services Team

## EDUCATION AND RESOURCE SUMMIT

Approximately 300 people attended our 4th 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, palliative care, and sessions for caregivers. Maintaining our tradition, we also emphasized the unique experiences of veterans and the services available to support them. We were fortunate to welcome a closing keynote address from Dr. Ajay Sampat, a neurologist who is living with ALS. Dr. Sampat's personal and unique perspective on the ALS experience provided inspiration and enhanced understanding to our entire audience.



The Long Island equipment loan closet

## EQUIPMENT PROGRAM

Our Equipment Loan, Home Accessibility, and Assistive Technology programs continue to be productive! We are increasing our scope to meet the growing needs of our community. In 2024 we added 165 new pieces of equipment to our program and delivered wheelchairs, hospital beds, and power patient lifts to families in all corners of our region. As always, this service is free of charge. In parallel, our assistive technology team conducts virtual home assessments on a regular basis, enhancing safety and accessibility in the home environments.



Our dedicated staff and clinic teams across Greater New York gathered at the Lou Gehrig Legacy Gala

## MULTIDISCIPLINARY CLINICS

ALS United Greater New York is proud to collaborate with nine multidisciplinary ALS clinic partners to provide comprehensive care. These partnerships, combined with our integrated wrap around care, ensure seamless support to the more than 1,200 families we served this year. Notably, this past year marked the unveiling of a new, state-of-the-art clinic space at Hackensack University Medical Center. This facility features private examination rooms for all disciplines on a single floor, enhancing the patient experience. Additionally, our ALS United affiliated clinics remain at the forefront of clinical trials and research, helping to reduce diagnostic wait times and enable more timely, proactive care.

# RESEARCH

**ALS United Greater New York is committed to supporting the most promising research projects and initiatives in the field and to date, we have invested nearly \$17 million in ALS research.**

As a signature program investment, ALS United Greater New York proudly supports the development of bright, young scientists through The Milton Safenowitz Postdoctoral Fellowship Program. The Safenowitz family, through our organization, founded the award in memory of Milton Safenowitz, who died of ALS in 1998. Fellows work with a senior mentor and receive extensive exposure to the ALS research community. Upon completion of their fellowship, more than 75% of the awardees remain in the field of ALS research, many going on to establish their own laboratories to continue studying ALS and mentor more ALS researchers along the way.

Additionally, we are proud to announce a new partnership this year. ALS United Greater New York, along with our 14 other ALS United member organizations, have taken another significant step in the battle against ALS by collectively supporting The Accelerating Medicines Partnership® in ALS (AMP® ALS) initiative. AMP® ALS brings together the resources and expertise of the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH), the Food and Drug Administration, Critical Path Institute, and other stakeholders from academia, life science companies, foundations, and patient-focused groups. This groundbreaking project aims to expedite the development of effective treatments for ALS, providing hope and progress for those affected by this relentless disease.

In May, Kristen Cocoman, President & CEO of ALS United Greater New York, attended the Target ALS Annual Meeting, uniting leaders across academia, biotech, pharma, venture capital, and nonprofits to advance ALS research.



**Kristen Cocoman, President & CEO ALS United Greater New York and Manish Raisinghani, CEO Target ALS.**

## ALS UNITED WAS PROUD TO SUPPORT THE FOLLOWING RESEARCH INITIATIVES IN 2024:

### The Milton Safenowitz Postdoctoral Fellowship Program

PREVENT ALS

Expanded Access

ALS Network Research Program

The Accelerating Medicines Partnership® in ALS

Target ALS Springboard Fellowship Program

The Northeast ALS Consortium (NEALS)



# ADVOCACY

## FEDERAL

In April several of our staff joined New Jersey advocate and person living with ALS, Melanie Craig and her family in Washington, D.C., to champion ALS-related legislative initiatives. Key priorities included the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act, Justice for ALS Veterans Act, and the ALS Better Care Act, each receiving positive responses from lawmakers.

Thanks to the advocacy efforts of our ALS United partners from New York and across the entire country, the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act was passed by Congress in the fall and signed into law by President Biden. The new law amends various Department of Veterans Affairs Authorities related to health care, economic opportunity, disability and memorial affairs, and veteran homelessness. As ALS progresses, veterans face an increased need for assistance and specialized care. This bill addresses these critical needs by enhancing access to home care and expanding caregiver support programs within the VA.

Staff from ALS United Greater New York participated in the I AM ALS Community Summit and the Third Annual DC ALS Awareness Event. They served as moderators and legislative captains while connecting with advocates from across the region. The highlight of the event was the I AM ALS flag display and ceremony on the National Mall, which honored those living with ALS and those we have lost.



The Craig Family, New York Senator “Chuck” Schumer and ALS United Greater New York Staff



I AM ALS Flag Display on the National Mall



U.S. Capitol



Advocates on “The Hill” in Washington, D.C.



ALS United Greater New York Staff and advocates gather for the I AM ALS Summit

# ADVOCACY

## NEW YORK

The 2024/2025 New York state budget held a significant victory for those living with ALS. An incredible \$25 million was allocated through the New York State budget for ALS and rare disease research. The Governor, whose mother passed away from ALS in 2014, demonstrated strong leadership in making this funding a reality. The \$25 million will support rare disease research and treatment, with a significant focus on ALS. This achievement highlights the power of partnership and advocacy in advancing ALS research and care.

In May, ALS United Greater New York, alongside 14 other health advocacy organizations, traveled to Albany advocating for laws to prevent genetic discrimination, particularly in life, long-term care, and disability insurance. These protections are vital, as 10% of ALS cases are hereditary, and families need access to genetic testing without fear of insurer bias. While these bills did not pass this year, we are committed to moving them forward in 2025.



New York State Capitol



Governor Hochul speaking at the Lou Gehrig Legacy Gala on the importance of ALS research



ALS Advocates in Albany

## NEW JERSEY

In early 2024, New Jersey Governor Phil Murphy proposed budget cuts that would slash ALS funding for state residents by 66%. In response, ALS United organizations testified before the Assembly and Senate Budget Committees, urging lawmakers to maintain funding at the \$1.5 million level which they had received in 2023. Unfortunately, while we actively worked with legislators to submit a resolution preserving this vital funding, the final budget was passed in July reflecting the Governor's cut. In 2025 ALS United Greater New York will again be actively working with elected officials to reinstate ALS funding to its prior amount.

This year marked significant progress in our mission to make ALS a reportable disease in New Jersey. Assemblymember McCoy introduced a bill, with Assemblymember Donlon, M.D., joining as a sponsor, while Senator Gopal introduced a companion bill in the Senate. The Assembly Health Committee approved the bill in December. Making ALS a reportable disease is critical to improving data collection and research. While the National ALS Registry captures important nationwide data, a state-level registry would allow for more targeted data collection and localized resource allocation. ALS United Greater New York is committed to working with legislators and partners to ensure this essential legislation reaches the Governor's desk in 2025.



Allison Giambra and her new personalized New Jersey license plate



New Jersey State Capitol



# WALK ALS

In 2024, we held Walk ALS events from May through October in New York City, Westchester, North Jersey, Jersey Shore, Long Island, and in the Hudson Valley. With more than 4,000 walkers, \$1.5 million was raised to support programs, services and research. We are grateful to the many dedicated and visionary team captains, event participants, volunteers, sponsors, and ALS advocates who participated.

Register to join us for one of our six walks in 2025 at [alswalks.org](https://alswalks.org).

## THANK YOU TO 2024 TOP TEN FUNDRAISING TEAMS!

Dani's Defenders

Pablo's Pals

Five O'Clock Lightning

Team Mike Leiderman

FOR THE LOVE OF JEMMA

Team Yorktel

Katz Walkers

The Watchung Cunninghams

Our Love For Mona

Zdzislaw Gabryszewski



## ALS IRON HORSE GOLF CLASSIC

The ALS Iron Horse Golf Classic celebrated its seventh successful outing at Sands Point Golf Club on Monday, August 12, 2024. More than 100 golfers raised over \$120,000 for our services and programs while enjoying a great day on the course.

Save the date for the Eighth Annual ALS Iron Horse Golf Classic on Monday, August 11, 2025.



The Iron Horse Party in May

## COMMUNITY FUNDRAISERS

Working with our local community to host their own fundraising events, many participants and volunteers built connections, raised ALS awareness, and generated more than \$380,000 in donations to support care services, advocacy, and research. Our top fundraisers included the annual Iron Horse Party, golf outings, sports competitions, and community Walks. If you have a hobby, interest, or passion and want to raise funds and awareness around ALS, contact Tara Connors, Senior Coordinator, Fundraising & Special Events at 212-720-3054 or [tconnors@als-ny.org](mailto:tconnors@als-ny.org).

# LOU GEHRIG LEGACY GALA

The ALS United Greater New York community gathered on November 12, 2024, for the annual Lou Gehrig Legacy Gala, a night dedicated to reflecting on the strides made in ALS research and care while honoring those who have become beacons of hope in the fight against ALS. Hosted by the renowned Jeremy Schaap, with special guest Bob Costas, the event recognized outstanding individuals who have made significant contributions to ALS research, care, and advocacy.

The 2024 Jacob K. Javits Lifetime Achievement Award was presented to Daniel L. Doctoroff, founder of Target ALS and former NYC Deputy Mayor, for his commitment to ALS research and advocacy. We were honored to have the Governor of New York, Kathy Hochul, join us to present Dan Doctoroff with the Javits Award. For Governor Hochul, the battle against ALS is personal, having lost her mother to the disease in 2014. Additionally, we proudly recognized David Lubars with the Champion Award for his decades long commitment to raising awareness through his creative work as Chief Creative Officer, BBDO Worldwide and as a dedicated board member of ALS United Greater New York.

The Lou Gehrig Sports Award was presented to three exceptional figures in the sports world who exemplify the resilience, strength, and leadership that defined Lou Gehrig's legacy. New York Rangers legend Adam Graves, New York Jets punter Thomas Morstead, and John Sterling, New York Yankees iconic radio play-by-play announcer, were celebrated for their exceptional achievements on the field and profound contributions beyond it.

The Gala's impact extended beyond heartfelt speeches and awards. With generous contributions from supporters, the event raised nearly \$700,000 adding to the more than \$26 million raised by the Lou Gehrig Legacy Gala over the years. These funds enable ALS United Greater New York to provide essential care and resources to ALS patients while advancing research to find a cure.



**Lou Gehrig Legacy Gala honorees: David Lubars, Thomas Morstead, Dan Doctoroff, John Sterling, and Adam Graves, with Allen Popowitz and Kristen Cocoman**



**Governor Kathy Hochul and Dan Doctoroff**



**Lou Gehrig Legacy Gala at Pier Sixty**



**Lou Gehrig Legacy Gala attendees with Bob Costas**



# EVENTS

## ALS AWARENESS DAYS AT NEW YORK BALLPARKS

ALS United Greater New York celebrated the legacy of Lou Gehrig with the New York Mets, the New York Yankees, and the Brooklyn Cyclones in 2024. We were joined by many friends and family at Citi Field on Sunday, June 2nd for the 4th annual Lou Gehrig Day, which was commemorated across all Major League Baseball parks on that date. On Thursday, July 4th, we were honored to be on the field with Her ALS Story, I AM ALS, ALS Ride for Life, and Quinn for the Win at the New York Yankees game to help celebrate ALS Day and honor the legacy of Lou Gehrig on the 85th anniversary of his “Luckiest Man Alive” speech. On Saturday, July 20th, the Brooklyn Cyclones held ALS Awareness Night at Maimonides Park in Coney Island as part of the Cyclones’ game against the Jersey Shore BlueClaws. Ron Reisman, from the Long Island Walk Team FOR THE LOVE OF JEMMA, threw out the first pitch.



Lou Gehrig Day at Citi Field



Raising ALS awareness at Yankee Stadium with ALS United Greater New York, Quinn for the Win, ALS Ride for Life, Her ALS Story, and I AM ALS



Ron Reisman throws out the first pitch for the Brooklyn Cyclones

## TEAM ALS

Over the course of 2024 Team ALS raised more than \$400,000, thanks to the efforts of 95 athletes hailing from various corners of the world, including New Zealand, California, Colorado, Florida, and a significant representation from our local community in Greater New York. These athletes participated in the TCS New York City Marathon, United Airlines NYC Half, TD Five Boro Bike Tour, and individual endurance events. We are actively recruiting participants to join our 2025 Team ALS endurance events. If you are interested, please contact Tara Connors at 212-720-3054 or [tconnors@als-ny.org](mailto:tconnors@als-ny.org).





# EVENTS



**ALS United Greater New York Walk Kick-Off**



**ALS United Greater New York at the Quinn for the Win Ice Bucket Challenge**



**NASDAQ Ice Bucket Challenge**



**Trisha Keery's Team at the Orangetown Ice Bucket Challenge**



**Cocktails and Conversations at the New York Genome Center**

## A YEAR OF IMPACTFUL ALS AWARENESS AND COMMUNITY CONNECTION

This year, we began with an inspiring Walk ALS Kick-Off event on March 18th at Madison Square Garden. Members from over 40 Walk Teams across New York and New Jersey gathered to celebrate, connect, and energize for the impactful season ahead of the 6 Walks across our region.

This summer, we marked the 10th Anniversary of the Ice Bucket Challenge with three unforgettable events. The celebration began with the Quinn for the Win Ice Bucket Challenge in Yonkers, followed by the iconic moment of ringing the opening bell at NASDAQ, symbolizing the significance of our shared fight against ALS. The season culminated with the Orangetown Ice Bucket Challenge in Rockland County, which raised an outstanding \$25,500.

On September 12th, we hosted *Cocktails and Conversations* on the rooftop terrace of the New York Genome Center. This gathering brought together Board members, staff, patients, families, and donors to foster connections and strengthen our collective commitment to find a cure.

**Each event underscored the power of unity and awareness in driving change and supporting those impacted by ALS.**

September also saw a heartwarming Hudson Valley Patient and Family Day at Melzingah Tap House in Beacon, NY, bringing together families impacted by ALS from across the Hudson Valley.

As the year concluded, we introduced the Joseph Cotrone Holiday Dinner Program at Patrizia's. A new tradition reflecting our dedication to care, connection, and compassion.



**Hudson Valley Patient and Family Day at Melzingah Tap House**

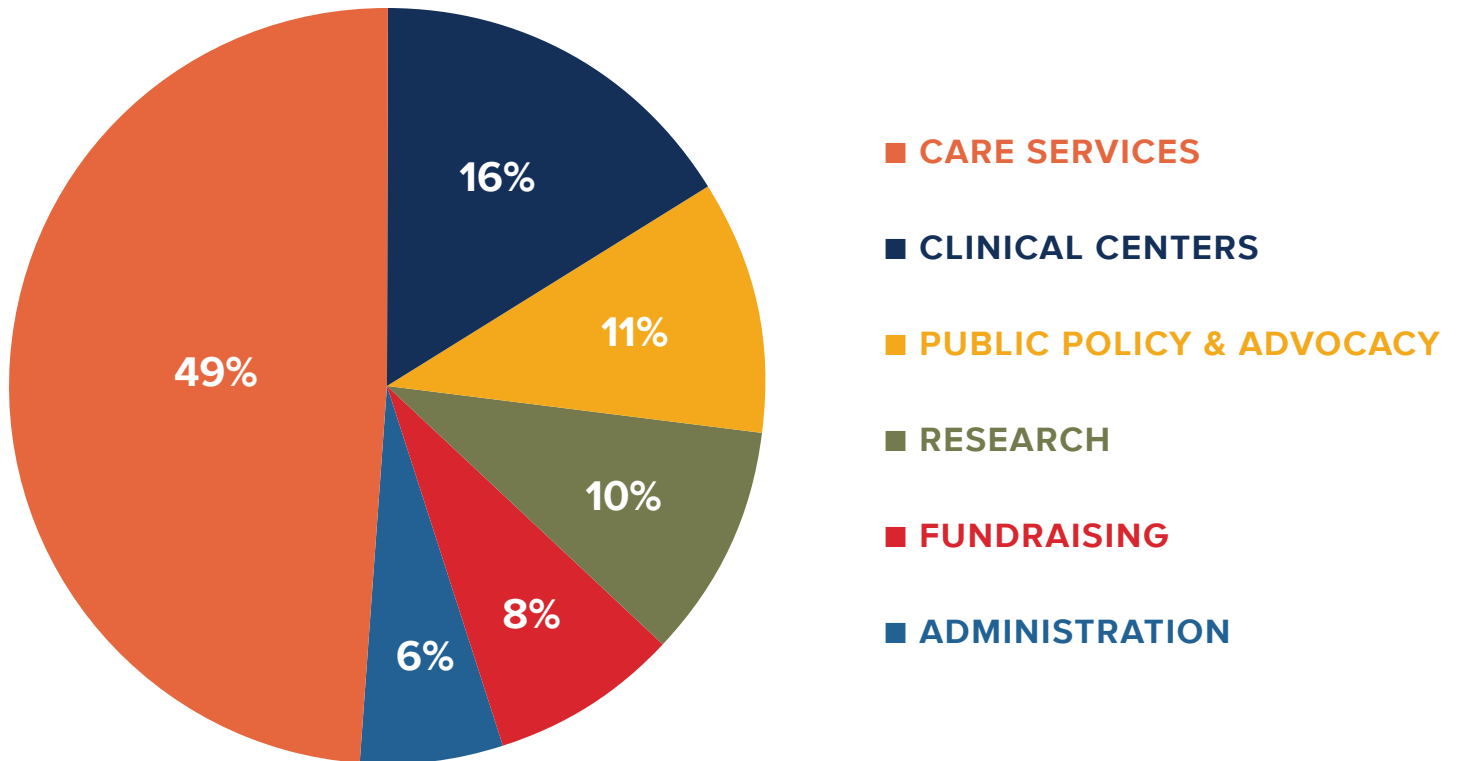


**Joseph Cotrone Cigar Dinner at Patrizia's to support ALS United Greater New York**

# FUNDRAISING

The 2024 fiscal year ending January 31, 2025, brought in nearly **\$6 million** across all fundraising, services, including events, major gifts from individuals, foundation grants, and bequests. The dedicated support from donors at every level enhances our vital programs to best serve people living with ALS and their families across the Greater New York community.

## WHERE ARE YOUR DONATIONS GOING?



**1,238** people with ALS were served in 2024

**1,113** people attended support groups

**734** patients received care and clinical management of ALS through one of our 9 multidisciplinary clinics

**1,038** home visits were conducted

**1,123** pieces of durable medical equipment and augmentative communication devices were distributed

**228** rides were provided for patients to attend appointments at one of our multidisciplinary clinics

**136** grants totaling **\$293,098** were made to patients to cover in-home health care, home accessibility upgrades and additional expenses such as prescription co-pays

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 2024, we earned our eleventh consecutive Four-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.



# THANK YOU

## PLEASE JOIN US IN THANKING OUR TOP DONORS OF 2024

Andrew Abramsky  
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ALS Ride For Life, Inc.  
Amylyx Pharmaceuticals  
Anonymous  
Lillian Arlia  
Bargold Storage Systems, LLC  
BBDO USA, LLC  
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David and Lynette Zinberg

**Thank you to everyone who contributed to the mission of ALS United Greater New York in 2024!** 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 or [vbanks@als-ny.org](mailto:vbanks@als-ny.org)**

## 2025 EVENTS

### SUNDAY, MARCH 16

United Airlines NYC Half Marathon

### SUNDAY, APRIL 27

NYCRuns Brooklyn Experience  
Half Marathon

### SATURDAY, MAY 3

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

### SUNDAY, MAY 4

TD Five Boro Bike Tour

### MAY 15 –16

Education and Resource Summit  
Virtual

### SATURDAY, MAY 31

Walk ALS Westchester  
Manhattanville University  
Purchase, NY

### SUNDAY, JUNE 2

Lou Gehrig Day  
Throughout Major League Baseball

### SUNDAY, JUNE 8

Walk ALS North Jersey  
Saddle River Park  
Saddle Brook, NJ

### MONDAY, AUGUST 11

ALS Iron Horse Golf Classic  
Sands Point, NY

### SATURDAY, SEPTEMBER 13

Walk ALS Jersey Shore  
Long Branch, NJ

### SATURDAY, SEPTEMBER 20

Walk ALS Long Island  
Eisenhower Park  
East Meadow, NY

### SUNDAY, OCTOBER 19

Walk ALS Hudson Valley  
Walkway Over the Hudson  
Highland, NY

### SUNDAY, NOVEMBER 2

TCS New York City Marathon

### TUESDAY, NOVEMBER 11

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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*\*in memoriam*



ALS UNITED GREATER NEW YORK | 42 Broadway, Suite 1724, New York, NY 10004  
als@als-ny.org | 212-619-1400 | **ALS-NY.ORG**