

# THE IMPACT OF YOUR GIVING

## AN ANNUAL REVIEW OF SUCCESSES & ADVANCEMENTS **2022**

**A**s we embark on our journey into 2023, we would like to take the opportunity to reflect on all the successes in the past year that have been made possible because of you. 2022 was a significant year of growth and together we are truly *making strides in the fight against ALS*. We have seen research advancements, major advocacy wins, and we have generated an increase of care service offerings for the Greater New York ALS community.



The Jones family attending the 2022 Lou Gehrig Day at Yankee Stadium on June 2nd, 2022 in memory of James Jones.

Within these pages of our annual Impact Report, you will read about the accomplishments of 2022 and our plans for the year to come. Customized program updates are detailed including respite and ramp grants, equipment loans, and new support groups. Our dedicated team of nurses, social workers, and assistive technology specialists continue to provide seamless care to people living with ALS and their families who rely on these vital resources. We are working harder than ever to serve this community on all fronts and eager to keep building upon our shared successes. One of our first endeavors for 2023 is launching our brand new website that provides more information, access to educational videos and ways to become involved with the Greater New York Chapter. Visit us at [als-ny.org](https://als-ny.org).



### 2022 HIGHLIGHTS

CARE SERVICE SUCCESSES | ADVOCACY WINS | RESEARCH DEVELOPMENT | FUNDRAISING OUTCOMES

# THE IMPACT OF YOUR GIVING

In 2022, **The ALS Association Greater New York Chapter** continued our hybrid programs and services while also expanding our offerings. As our team continued providing support through virtual platforms, we unveiled our new program, T.L.C. (Talk. Learn. Connect.). T.L.C. offerings are chapter-wide, virtual presentations from a variety of ALS experts as well as opportunities for specified audiences (ie. Newly Diagnosed) to convene in order to share topics of mutual interest. T.L.C., together with our expanded grant offerings and on-going continuity of care to approximately 1,000 patients, has made 2022 our busiest year!

## **Virtual Education Summit**

In May of 2022, over 250 members of the ALS community gathered online for the second annual ALS Association Greater New York Chapter Education and Resource Summit. Building upon the previous year's success, it was important to the chapter that we continue to provide educational resources to the ALS community. This ensured that we remain at the forefront of thought leadership and the dissemination of cutting edge tools to the ALS community. Fourteen sessions took place over two days and featured presentations from leading neurologists and experts working in the ALS space. Topics included: Genetics in ALS, Nutritional Considerations, Intimacy and ALS, Advancements in ALS Research, and Clinical Trials among others. All videos from the Summit are available on the Chapter's YouTube channel.

## **James J. Peters Department Of Veteran Affairs Medical Center Certification**

We are proud to announce that the James J. Peters Department of Veteran Affairs Medical Center has successfully received certification as a Treatment Center of Excellence by the ALS Association. To commemorate this milestone, the association awarded Dr. Marinella Galea, Chief of Spinal Cord Injury and Disorders, Director of the ALS Clinic, Co-Director of MS Regional Center at The James J. Peters VAMC on October 20, with a plaque marking its designation. "We are proud of the longstanding commitment that the Bronx VA's ALS Center and our chapter has had together providing excellent care and supportive services to people with ALS in the community and beyond," said Kristen Cocoman, President & CEO of The ALS Association Greater New York Chapter. To become a Certified Treatment Center of Excellence, each clinic must meet The ALS Association's clinical care and treatment standards, based on AAN Practice Parameters, participate in ALS-related research, and successfully complete a comprehensive site review.

## **Equipment Loans**

The Greater New York Chapter provides short term and extended loans of recommended Durable Medical Equipment and Assistive Technology to individuals with ALS. Access to loaned equipment may be necessary because of delays in acquisition, or some items may not be covered by insurance. In either circumstance the Equipment Loan Program provides equipment at no cost to the recipient or family. We partnered with vendors to deliver 700 pieces of Durable Medical Equipment and Assistive Communication Equipment to our families.

## **Multidisciplinary Clinics**

The Greater New York Chapter 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.





### ***The Justice for Veterans Act***

Military veterans are at a greater risk of being diagnosed with ALS than those who did not serve in the military and therefore ALS is considered a service-connected disease. For veterans who die because of a service-related disease, their families are eligible for an increased compensation benefit. However, to be eligible, the veteran must live with the service-related disease for a period of 8 years. This is unfair to the families of veterans with ALS since life expectancy upon diagnosis is between 2-5 years. Advocacy this year increased support for The Justice for ALS Veterans Act which was introduced in the House and Senate in 2021 and would make it possible for surviving spouses of veterans who die from ALS to receive the increased Dependency and Indemnity Compensation regardless of how long their loved one lived with the disease after diagnosis.

### ***Increased State Funding***

The Chapter continued to receive state funding by both New York and New Jersey state budgets for 2022. Thanks to the testimony of Al Jeffries of New Jersey, advocate and person living with ALS, our New Jersey funding stayed steady at \$1 million dollars. This funding allowed the Chapter to:

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

### ***Support of Copay Accumulator Adjustment Legislation***

The ALS Association Greater New York Chapter stood with over 65 health organizations in supporting New York Legislation S.5299/A.1741, which would significantly help reduce the out-of-pocket healthcare costs for our community. Like many people living with complex medical conditions, those with ALS must take various drugs to maintain their health. The copays associated with acquiring them significantly add to this crushing financial burden.

Insurers and pharmacy benefit managers increasingly use copay accumulator adjustment programs to prevent such assistance from counting towards patient cost sharing, such as their deductible or annual out-of-pocket maximum. In effect, the insurer gets to “double-dip” by demanding payment of out-of-pocket costs: first from copay assistance programs and then again from patients.

The ALS Association Greater New York Chapter supported all efforts to prohibit copay accumulator adjustment programs. The legislation passed both houses and was signed by Governor Hochul on December 23rd.

### ***Research***

The U.S. Food and Drug Administration approved AMX0035 (Relyvrio) for the treatment of ALS in September 2022. Twice in 2022, The ALS Association leadership and ALS community advocates testified before the FDA’s advisory committee, imploring them to approve AMX0035. After the advisory committee narrowly voted against the approval, The Association circulated a letter signed by several dozen leading ALS clinicians telling the FDA they want to be able to discuss AMX0035 with their patients as a viable treatment option for ALS. When the FDA Advisory Committee reconvened, advocates again testified before the committee on the need for urgency. The committee finally voted unanimously to recommend approving the drug in September 2022.

The ALS Association supported the development of AMX0035 with a \$2.2 million grant in 2016 – one of the first research grants funded with ALS Ice Bucket Challenge donations. As a standard provision in philanthropic support for drug development, the grant included a repayment provision allowing the Association to recover up to 150 percent of its support, or up to \$3.3 million. The funds will be reinvested into ongoing global research into treatments and, ultimately, a cure.



## FUNDRAISING OUTCOMES

**T**he fiscal year ending January 31, 2023, brought in \$6 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 in order to best serve people living with ALS and their families. While we are incredibly grateful to everyone, we would like to highlight a few extra special donors that made this year memorable.



### ***Milton and Marilyn Safenowitz Family Foundation —***

The Safenowitz family has been an integral part of our family for over 21 years. Their enduring support of research initiatives, including the Milton Safenowitz Postdoctoral Fellowship Program, as well as our Care Services Programs, continue to be instrumental for the Chapter and across the landscape of ALS research advancements.



### ***Cathy Miller, For the Love of Jemma —***

As a longtime supporter of the Long Island Walk to Defeat ALS and team captain of *For the Love of Jemma* Cathy has been instrumental in collectively raising \$2 million in support of research over the past 17 years. Cathy and her team, who walk in honor of their cousin Jemma, as well as all patients and families throughout the community, are committed to helping the Chapter raise funds in the fight against ALS.

**Thank you to everyone who contributed to the mission of The ALS Association Greater New York Chapter in 2022. Without your support, our work would not otherwise be possible.**



**For more information on how you can expand your mission-based giving through various mechanisms, such as IRA rollovers, Charitable Remainder Trusts, gifts of stock and securities, or estate planning, please contact:**

Vivian Banks

Director of Individual and Institutional Giving

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

# WHERE ARE YOUR DONATIONS GOING?

.83 CENTS OF EVERY DOLLAR RAISED GOES TO OUR PROGRAMS

**PATIENT SERVICES**

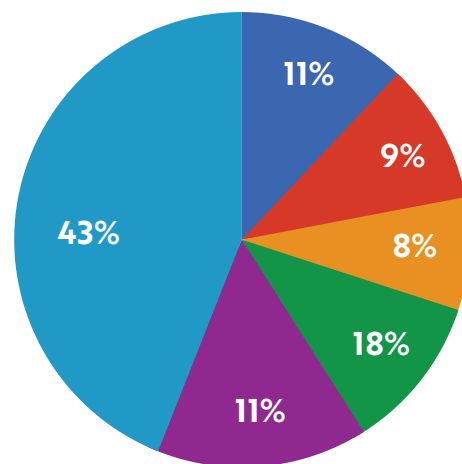
**RESEARCH**

**CLINICAL CENTERS**

**FUNDRAISING**

**PUBLIC POLICY & ADVOCACY**

**ADMINISTRATION**



**1,137** people living with ALS served

**1,430** people attended **131** support groups

**159** active global research projects in **10** countries

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

**835** virtual home visits

**\$241,000** in monetary grants to cover in-home health care, home accessibility upgrades, and additional expenses such as prescription co-pays, and more

**Nearly 700** pieces of durable medical equipment and/or communication devices loaned free of charge

**176** rides provided free of charge for patients to attend appointments at Chapter multidisciplinary clinics

## PLEASE JOIN US IN THANKING OUR TOP DONORS OF 2022

ALS Ride for Life  
 Andrew Abramsky  
 Amylyx Pharmaceuticals  
 BBDO  
 BEB Capital  
 Caroline Beinstock & Doug Rodriguez Charitable Fund  
 Benevity Community Impact Fund  
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 The Birk's Works Foundation  
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 Alan and Penny Griffith  
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 Holzer Family Foundation  
 Hospital for Special Surgery  
 The Hyde and Watson Foundation  
 Iron Horse 4 Mile Run  
 The Marian B. and Jacob K. Javits Foundation  
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 Katz Realty Group  
 Lenny and Amy Katz  
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 The Danielle Kirrane Foundation  
 Roger Klauber Family Foundation  
 Richard H. Lasdon Charitable Trust  
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 Martha Olson-Fernandez Foundation  
 Paralyzed Veterans of America Education Foundation  
 Park Pictures  
 Estate of Stefan Pischinger  
 The Margaret and Peter Philips Family Foundation  
 The Provident Bank Foundation  
 Christopher and Dana Reeve Foundation  
 Cynthia Rimpo  
 Proskauer Rose, LLP  
 Milton and Marilyn Safenowitz Family Foundation  
 Daniel and Sara Sapdin  
 The Sunshine Foundation  
 The Tow Foundation  
 Stanley L. Trela  
 Arthur and Joanne Weinbach  
 Yorktel



## EVENTS

# WALK TO DEFEAT ALS

## \$1,500,000 RAISED

The Greater New York Chapter's 2022 Walk to Defeat ALS Program was a big success, thanks to the dedication of the walkers. We had more than 4,000 walkers and 470 teams participate at all six walks throughout the spring and fall. **Make sure to register for one of our six walks in 2023 at [alswalks.org](https://alswalks.org)!**



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

FOR THE LOVE OF JEMMA

WAYNE'S WARRIORS

TEAM SCOTT

WIN THE FIGHT

TEAM JANICE

TEAM JAY

TEAM MIKE LEIDERMAN

STORMIN 4 NORMAN

TEAM REITZ

KATZ WALKERS



## TEAM ALS

The Greater New York Chapter was a Silver Level Charity Partner of the TCS New York City Marathon on November 6, 2022. A team of 61 runners from across the country raised nearly \$340,000 to support the ALS community. *We are currently recruiting for upcoming Team ALS events including the NYC Half Marathon in March, the TD Five-Boro Bike Tour in May, and the TCS NYC Marathon in November.*



## COMMUNITY FUNDRAISERS

Every year many third-party community fundraisers are hosted to benefit the Chapter. In 2022, these fundraisers raised more than \$520,000 to benefit the Greater New York community. Our top fundraisers included the annual Iron Horse Party in May, which raised more than \$280,000, several golf outings, and a community walk.



## THE ALS IRON HORSE GOLF CLASSIC

More than 100 golfers joined us for the fifth annual outing on Tuesday, August 9, 2022 at Sands Point Golf Club in Sands Point, NY. They enjoyed a great day on the course and helped raise over \$125,000 toward our programs and services. *Save the date for the Sixth Annual ALS Iron Horse Golf Classic in August 2023.*





# THE LOU GEHRIG LEGACY GALA

On Monday, November 7, 2022, we hosted The Lou Gehrig Legacy Gala in person for the first time since 2019. This year's program was both moving and inspirational, with a focus on the National Hockey League, a community that has experienced the devastation of an ALS diagnosis. The evening was emceed by Q104.3 radio personality and Chapter Board member Ken Dashow. The Jacob K. Javits Lifetime Achievement Award was presented to Gary Bettman, Commissioner of the National Hockey League. Our Lou Gehrig Sports Awards were given to New York Yankees pitcher Nestor Cortes, and NHL legends Pat LaFontaine and Henrik Lundqvist. Rod Gilbert, former New York Rangers legend and a 2003 Lou Gehrig Sports Award recipient, was posthumously bestowed with the Champion Award. We were privileged to view a special tribute video of Chris Tschupp, who sadly lost his battle to ALS two weeks prior to the Gala. Chris's wife, Sofia, spoke after the video played, and her story was powerful and inspiring for everyone at the event. Proceeds from The Lou Gehrig Legacy Gala allow us to fund the most promising research initiatives and provide the highest quality support services for people with ALS and their families in the Greater New York area. **Mark your calendar for next year's Gala – Monday, November 6, 2023 at Pier Sixty in New York.**



## LOU GEHRIG DAY

Major League Baseball officially designated June 2nd as Lou Gehrig Day. This date now and forever honors Lou's legacy on the field, and raises awareness about ALS throughout the world. The Greater New York Chapter was proud to celebrate the 2nd annual Lou Gehrig Day with over 400 friends and family at Yankee Stadium. We were joined by **ALS Ride for Life** for a pregame onfield presentation.



## 2023 EVENTS

### SUNDAY, MARCH 19

United Airlines NYC Half Marathon

### SATURDAY, MAY 6

New York City Walk to Defeat ALS  
Hudson River Park, NY

### SUNDAY, MAY 7

TD Bank Five Boro Bike Tour

### MAY 11 – 12

Education and Resource Summit

### FRIDAY, JUNE 2

Lou Gehrig Day  
Throughout Major League Baseball

### SUNDAY, JUNE 4

Westchester Walk to Defeat ALS  
Manhattanville College,  
Purchase, NY

### SUNDAY, JUNE 11

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

### AUGUST, TBD

ALS Iron Horse Golf Classic  
Sands Point, NY

### SATURDAY, SEPTEMBER 23

Long Island Walk to Defeat ALS  
Eisenhower Park,  
East Meadow, NY

### SATURDAY, SEPTEMBER 30

Jersey Shore Walk to Defeat ALS  
Long Branch, NJ

### SUNDAY, OCTOBER 15

Hudson Valley Walk to Defeat ALS  
Walkway Over the Hudson,  
Highland, NY

### SUNDAY, NOVEMBER 5

TCS NYC Marathon

### MONDAY, NOVEMBER 6

The Lou Gehrig Legacy Gala  
Pier Sixty, NYC

## OUR MISSION

The ALS Association's mission is 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.

As one of The ALS Association's leading chapters, the Greater New York Chapter plays a major role in promoting the mission of The ALS Association by:

- Providing quality services to patients and families living with ALS throughout the greater New York area, including New York City, Long Island, Westchester County, the Hudson Valley, and northern and central New Jersey.
- Funding aggressive, cutting-edge research to find a cure that utilizes the newest techniques and fosters collaborative initiatives among government agencies, the private sector and scientists.
- Supporting The ALS Association's national advocacy program to expand government support of research and elicit programs to make treatments and care accessible and affordable for all ALS patients.
- Heightening awareness of ALS in order to stimulate volunteerism, scientific and healthcare community activism, and public support that is essential to the fight against ALS.

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