

With You, There is Hope for a Brighter Future

It's February 1st as I write this and we are about to hit the gas on what I am confident will be a year filled with success and much progress. But first, a quick look into the rear view mirror to recognize that in 2021, together we accomplished so much!



The Gluck Family

This past holiday season we saw unprecedented support from our community, thanks to a generous matching grant of \$200,000 from the Gluck Family Foundation. With your help, we were able to meet and exceed this matching opportunity, which was the first of its kind for our Chapter — and its impact will be far-reaching. Your generosity means the ALS community can continue to depend on all the services and programs The Greater New York Chapter provides without any interruption.

Within these pages of our Year In Review, you will read about our advocacy wins, awareness efforts and how we are working harder than ever to allocate funding to the Association's global research program. You will read about our incredible programs such as our financial grants and equipment loan programs and our dedicated team of nurses, social workers, and assistive technology specialists who continue to provide the seamless care those living with ALS and their families have come to count on.

As we move into 2022, we are firing on all cylinders and look forward to building upon our strong foundation as we expand services. We will continue to work on providing sustained access to telehealth, additional financial support to those in need and increasing the number of pieces of durable medical equipment and communications devices loaned to families. Our advocacy efforts will only grow, and in 2022, as always, we will continue providing the vital resources needed to this community. On every front we are working to do more and provide more to the families we serve. I hope you will join us in 2022!

Thank you.

Kristen Cocoman, President and CEO



2021 Highlights



**Care Services
Successes**



**Advocacy
Wins**



**Research
Advancements**



**Fundraising
Outcomes**

Care Services Successes

As we look back on 2021, The ALS Association Greater New York Chapter continued the hybrid programs and services that fit our patient community during the pandemic while also exploring opportunities to expand. Not only did our programmatic options increase, offering a rich and robust selection of educational workshops and support groups, but our team continued working around the clock through virtual platforms to keep the lines of communication open. We provided continuity of care to 1,133 people with ALS through ongoing virtual support, equipment training, multidisciplinary treatment options, and respite care grants.



Virtual Education Summit — In April of 2021, over 300 members of the ALS community gathered online for the first annual ALS Association Greater New York Chapter Education and Resource Summit. While we were unable to gather everyone together in person, it was important to the Chapter that we continue to provide educational resources to the ALS community. This ensured that we remained up-to-date on all that is taking place in the ALS landscape, and the tools that people living with ALS and their families have at their disposal. Nineteen sessions took place over three days and featured presentations from the leading neurologists and experts working in the field of ALS. Topics included: Advances in ALS Research, Clinical Trials, and Enrollment, to Intimacy and ALS, and How to Be a Strong Self Advocate, among others. All videos from the Summit are available on the Chapter's YouTube channel.



Staff of the Mount Sinai Beth Israel/Mount Sinai Downtown Union Square / ALS Association Greater New York Chapter ALS Center

Equipment Loans — We partnered with vendors to deliver close to 400 pieces of Durable Medical Equipment and Assistive Communication Equipment.

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.

Advocacy Wins

While the pandemic continued throughout 2021, your advocacy for those living with ALS produced some incredible wins, both on the federal and state level.

Accelerating Access to Critical Therapies for ALS Act – Thanks to the incredible advocacy of the ALS community, the Accelerating Access to Critical Therapies (ACT) for ALS Act passed Congress and was signed into law by President Biden on December 23, 2021. This act authorizes \$100M over five years for ALS research and creates the first federal entity explicitly charged with developing treatments for neurodegenerative diseases. Specifically, the bill would create a new:

- Framework for delivering experimental therapies to people with ALS
- Research grant program at the FDA for rare neurodegenerative diseases
- Collaborative for Rare Neurodegenerative Diseases at the Department of Health and Human Services (HHS) to coordinate federal efforts on developing and approving treatments and cures

AMX0035 – The FDA heard from ALS advocates and medical professionals in July 2021 regarding the necessity of getting drugs fast-tracked through the government process. Following the hearing, Amylyx Pharmaceuticals announced in September they would move forward with their intention to submit a New Drug Application (NDA) to the U.S. Food and Drug Administration (FDA) for AMX0035 for the treatment of ALS. On December 29, 2021, the FDA granted Priority Review and assigned a Prescription Drug User Fee Act date for AMX0035 of June 29, 2022, the target date by which the FDA intends to complete its review and take action on the NDA.

Increased State Funding – The Chapter saw an increase in state funding by both New York and New Jersey state budgets for 2021. New York state funding increased by 50% and thanks to the testimony of Joe Luistro, NJ advocate and person living with ALS, our New Jersey funding increased by 67%. This increased funding allowed the Chapter to:

- Expand outreach to ALS Community
- Grow Equipment Loan Program
- Increase respite grants



Joe Luistro, who retired from the Edison Township Police Department, is seen here with his wife, Millie

Research Advancements

Our collaborative and global approach to funding research continues to lead to significant discoveries by top ALS scientists around the world. Even in the face of the continued pandemic, our efforts did not slow. Since the inception of the Greater New York Chapter, with our 2021 contribution, we have invested more than \$15 million in ALS research. In funding both local and global research programs, The Greater New York Chapter has supported initiatives such as:

- The ALS Research Program at the New York Genome Center
- Milton Safenowitz Postdoctoral Fellowship Program
- Clinical Studies and programs in the area of drug development



Fundraising Outcomes

Walk to Defeat ALS Over \$1,000,000 Raised!

The Greater New York Chapter's 2021 Walk to Defeat ALS Program had a very robust schedule last fall, hosting five in-person Walks, and one virtual, throughout September and October. The Walks overall were a success, thanks to the dedication of the walkers.

Make sure to register for one of our six walks in 2022 at alswalks.org!



Thank You to Our Top Ten Fundraising Teams!

- For The Love of Jemma
- McCarthy Strong
- Win the Fight
- Katz Walkers
- Our Love For Mona
- Team J.A.C.K.
- Strong Andy
- Stormin 4 Norman
- Hugh's Hikers
- Team Yorktel

Through the challenge of a continuing pandemic, the fiscal year ending January 31, 2022 **brought over \$2M from non-event fundraising, including major gifts from individuals, foundation grants, and bequests.** The steadfast support from donors at every level, makes a positive difference in the lives of many. This impact enhances our vital programs for people living with ALS and their families. While we are incredibly grateful for all of you, we would like to highlight those donors who have made especially meaningful gifts this year:

Milton Safenowitz Family Foundation – The Safenowitz family has been an integral part of our family for more than 20 years. Their enduring support of research initiatives, such as 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.

The Gluck Family Foundation – As longtime supporters of the Chapter, the Gluck Family Foundation provided an exceptional gift this holiday season of an incredible matching grant opportunity for our year-end campaign that was exceeded by our wonderful donor community. The Gluck Family continues to be a special ally in the fight against ALS.

Thank you to all of our caring and dedicated donors who so admirably contribute to the mission of The ALS Association Greater New York Chapter. Without each of you, our ongoing work would not be possible for this ALS community.

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:

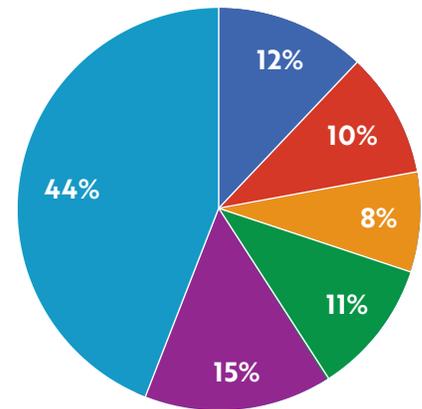
Vivian Banks, Director of Individual and Institutional Giving
212-720-3051 or vbanks@als-ny.org

Where Are Your Donations Going?

.82 Cents of Every Dollar Raised Goes to Our Programs

- 1,133** people living with ALS served
- 1,638** people attended **136** support groups
- 162** active research projects worldwide
- 677** patients received care and clinical management of ALS through one of our **10** multidisciplinary centers
- 495** virtual home visits

- Patient Services
- Clinical Centers
- Public Policy & Advocacy
- Research
- Fundraising
- Administration



\$60,000 in monetary grants to cover **2,400** hours of in-home health care and additional expenses such as prescription co-pays, and more

Nearly 400 pieces of durable medical equipment and/or communication devices loaned free of cost

122 rides provided free of cost for patients to attend appointments at Chapter multidisciplinary clinics

PLEASE JOIN US IN THANKING OUR TOP DONORS OF 2021!

- Andrew Abramsky
- BBDO
- Eric Berniker
- Estate of Michael F. Brady
- BEB Capital
- Tom Carroll
- Wendy Cherwin
- The Cinque Foundation
- The Cobb Foundation
- Columbia Bank Foundation
- Bayley and Michele Davis
- Echo Street Capital
- Ike, Molly & Steven Elias Foundation
- The Barbara Epstein Foundation
- Estate of Frances Fried
- Dr. Concetta Gallo
- Molly Garber
- Geico Philanthropic Foundation
- The Gluck Family Foundation
- Dana Gluck and Sean Twomey
- Alan and Penny Griffith
- Mary W. Harriman Foundation
- Mary and Kathleen Harriman Foundation
- Helen Hoffritz Charitable Trust
- Holzer Family Foundation
- The Marian B. and Jacob K. Javits Foundation
- Estate of Dorothy Kallman
- Katz Realty Group
- Lenny and Amy Katz
- Laurie Kayden Foundation
- Thomas Kirrane
- The Fay J. Lindner Foundation
- Mr. and Mrs. Jeffrey H. Loria
- Major League Baseball
- Jack and Nancy Marino
- Robert and Joan Matloff
- Mitsubishi Tanabe Pharma America, Inc.
- Prue and Jay Mortimer
- Domenick Muro
- Wendy and John Neu
- The Nuti Family
- Park Pictures
- Estate of Stefan Pischinger
- Ride For Life, Inc.
- Cynthia Rimpo
- The Milton and Marilyn Safenowitz Family Foundation
- Daniel and Sara Sapadin
- Estate of Santa Scavuzzo Legano
- The Sunshine Foundation
- The Tow Foundation
- Stanley L. Trela
- Queensboro Chapter of Unico
- William and Jean VanCuren
- The Hyde & Watson Foundation
- Lauren Wechsler
- Joanne and Arthur Weinbach
- The Willow School

Events

The Lou Gehrig Legacy Gala – On Monday, November 8, 2021, we hosted our virtual Lou Gehrig Legacy Gala where three incredible women were awarded for their accomplishments in business and sports. The Jacob K. Javits Lifetime Achievement Award was presented to Jacqueline Kelman Bisbee, Founding Partner of Park Pictures and the Lou Gehrig Sports Award was given to Kim Ng, General Manager of the Miami Marlins and Sue Bird, WNBA Champion, five-time Olympic Gold Medalist.



A special tribute and Champion Awards were presented in memory of Dr. Christopher Pendergast and Pat Quinn, heroes of the ALS community. We were privileged to hear from Samone Jackson and her family as they described her life living with ALS. Proceeds from

the Lou Gehrig Legacy Gala allows 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 7, 2022 at Pier 60 in New York.



Area youth participating in ALS Youth Challenge

Community Fundraisers – Every year a number of third-party community fundraisers are held, including the ALS Youth Challenge, which encourages children of all ages to become involved in the fight against ALS. In 2021, these fundraisers raised nearly \$350,000 to benefit the Greater New York Chapter. Our top fundraisers included a Century Bike Ride from NYC to Montauk hosted by the Hendra family in memory of their father who passed away in March 2021 after a three-year battle with ALS, and a Golf Outing in Brooklyn, hosted by Thomas Kirrane, in memory of his wife, Danielle.



Berke Gursoy, Craig Williams, and Tommy Rogan

TEAM ALS – The Greater New York Chapter was a Silver Level Charity Partner of the 50th TCS New York City Marathon on November 7, 2021. A team of 53 runners from across the country raised nearly \$350,000 to support the ALS community. We are actively recruiting for the upcoming Team ALS events including: NYC Half Marathon in March, the TD Five-Boro Bike Tour in May, and the NYC Marathon in November.



Berniker Foursome at the ALS Iron Horse Golf Classic

The ALS Iron Horse Golf Classic – More than 80 golfers enjoyed the fourth successful outing on Thursday, August 12, 2021 at Sands Point Golf Club in Sands Point, NY. They enjoyed a great day on the course and helped raise over \$100,000 toward our programs and services. Save the date for the Fifth Annual ALS Iron Horse Golf Classic on Tuesday, August 9, 2022.

ALS Awareness Month – As part of May ALS Awareness Month, the Greater New York Chapter not only continued its *This is the Face of ALS* video project with three new stories directly from those living with the disease, we also offered a special online event, *An ALS Journey: Interview & Discussion*. WQXR radio host Elliott Forrest interviewed ALS activist and author, Jeremy Schreiber about his journey with the disease. Two-time TONY Award winner, James Naughton, pre-recorded selected excerpts of Jeremy’s book, *The Invisible Nation*, and joined Elliott to discuss his own closeness to the disease. You can watch the interview on our YOUTUBE channel. Sadly, Jeremy passed away in October of last year. His book is scheduled to be published posthumously this spring.



Elliott Forrest, Jeremy Schreiber, James Naughton



Lou Gehrig Day June 2, 2021

Major League Baseball officially made June 2nd 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 gather over 100 friends and family at Yankee Stadium and hear some of our own deliver Lou’s famous “Luckiest Man” speech from the Big Screen!

• 2022 EVENTS •

Sunday, March 20
United Airlines NYC
Half Marathon

Sunday, May 1
TD Bank Five Boro Bike Tour

Saturday, May 7
New York City Walk to
Defeat ALS at Pier 45,
Hudson River Park, NY

May 19 – 20
Education & Resource Summit

Thursday, June 2
Lou Gehrig Day
Throughout Major League
Baseball

Sunday, June 5
Westchester Walk to Defeat
ALS at Manhattanville College,
Purchase, NY

Sunday, June 12
North New Jersey Walk to
Defeat ALS at Saddle River
County Park, Saddle Brook, NJ

Tuesday, August 9
ALS Iron Horse Golf Classic

Saturday, September 17
Jersey Shore Walk to Defeat
ALS in Long Branch, NJ

Saturday, September 24
Long Island Walk to Defeat ALS
at Eisenhower Park,
East Meadow, NY

Sunday, October 16
Hudson Valley Walk to Defeat
ALS at Walkway Over the
Hudson, Highland, NY

Sunday, November 6
TCS NYC Marathon

Monday, November 7
The Lou Gehrig Legacy Gala

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.

ALS
ASSOCIATION
Greater New York
Chapter

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