

# THE ALS ASSOCIATION

## GREATER NEW YORK CHAPTER

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WWW.ALS-NY.ORG



**ALS Association**  
Fighting Lou Gehrig's Disease

**Greater New York  
Chapter**

# ANNUAL REPORT

YEAR ENDING JANUARY 31ST, 2007

# WHAT IS ALS?

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, is a fatal neuromuscular disease that attacks the motor neurons in the brain and spinal cord that control voluntary muscle movement. As these cells or motor neurons die, the muscles they control become weak and then nonfunctional. As the disease progresses, people with ALS become paralyzed, while their minds usually remain unaffected and aware of their bodies' deterioration.

ALS became known as Lou Gehrig's Disease when the New York Yankee great died of it in 1941. Outside of the United States, ALS is often referred to as Motor Neuron Disease.

# MISSION

To lead the fight to cure and treat ALS through global, cutting-edge research, and to empower people with Lou Gehrig's disease and their families to live fuller lives by providing them with compassionate care and support.

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

- Providing a comprehensive range of support services for patients and their families in the Greater New York area including New York City's five boroughs, Long Island, Westchester and Rockland counties 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.

# FACTS ABOUT ALS...

- ALS can strike anyone. It occurs throughout the world with no racial, ethnic, or social-economic boundaries.
- ALS is not a rare disease. Over 5,600 people in the U.S. are diagnosed with ALS every year—15 new cases every day.
- Each year, the number of people who learn they have ALS is about the same as those who find out that they have multiple sclerosis.
- The average life expectancy of an ALS patient is two to five years from diagnosis. About 20% live five years or more and up to 10% will survive more than ten years.
- ALS is not contagious.
- Approximately 5 to 10% of ALS is familial, occurring more than once in a family lineage.
- The care of an ALS patient can cost up to \$200,000 per year, depleting entire savings of patients and relatives.
- While there is no cure for ALS, with the proper medical management and support, people with ALS can lead more independent and productive lives.

# RESEARCH

The ALS Association is recognized as the preeminent organization in the quest to conquer ALS, setting the gold standard for world-class ALS research in the 21st century. We are guided by rigorous scientific standards and a spirit of collaboration with other organizations across the United States and around the world.

The ALS Association research program, led by a science director with more than 10 years of research experience, promotes collaboration among scientists while exploring innovative directions that embrace promising but unproven approaches. Because of its stringent review process, the research program celebrates credibility among the scientific community.

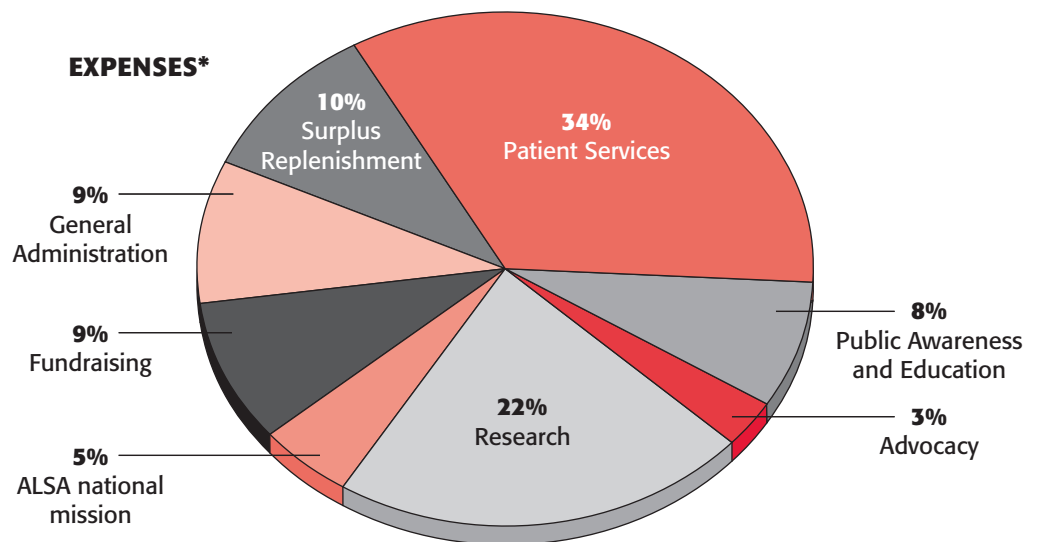
This cutting-edge research program utilizes these strategies . . .

- **TREAT ALS.** Launched in 2005, this initiative capitalizes on scientific and technological progress to accelerate drug discovery and realize effective new therapies for ALS independently and collaboratively.
- **Investigator-Initiated Research.** This program awards grants for innovative starter and one to three year research projects of high scientific merit and relevance to ALS. Scientists are encouraged to shape their research to learn the fundamentals about ALS. A prestigious review panel selects those studies which offer the greatest hope in unlocking the mysteries of ALS.
- **The ALS Association Initiated Research.** The ALS Association is taking the lead in identifying research to capitalize on new technologies, follow promising leads and explore scientific horizons.
- **The Milton Safenowitz Post Doctoral Fellowship for ALS Research.** A unique opportunity for recently graduated scientists to be on the cutting edge of scientific discovery. This fellowship program encourages bright young investigators to enter the field of ALS.
- **Scientific Workshops and Symposia.** To generate new research ideas and stimulate research applications from investigators new to ALS, ALSA holds scientific workshops throughout the year to bring together ALS researchers and non-ALS investigators renowned in their respective specialties to explore specific ALS-relevant topics.

# FINANCIAL PERFORMANCE

Revenue from all sources for the fiscal year of The ALS Association Greater New York Chapter ended January 31, 2007 was \$3,413,836, an all time high. Included in this amount is \$165,980 in in-kind donations of equipment used for our equipment loan program.

A copy of our complete audited financial report or our current 990 is available upon request.



\*Extracted from audited financials.

# PATIENT SERVICES

Since 1994, The ALS Association Greater New York Chapter has provided those with ALS and their families with the highest quality of care and support services. Serving over 600 patients with ALS in the Greater New York area, including New York City's five boroughs, Long Island, Rockland and Westchester counties, and northern and central New Jersey, we provide a wide array of services to help people with ALS manage the disease. These services include . . .



- **ALS Clinical Services Centers** at Beth Israel Medical Center\* in Manhattan, Robert Wood Johnson University Hospital\* in New Brunswick, New Jersey, and Stony Brook University Hospital in Stony Brook, Long Island. In fiscal year 2007, The ALS Association Greater New York Chapter sponsored and participated in **86** multi-disciplinary ALS clinic days at these centers, and provided critical care to patients.
- **Monthly support groups** for patients and care givers. In fiscal year 2007, we hosted **43** support group sessions for people with ALS, their families, and caregivers, providing a much needed outlet for those living with ALS.
- **In-home visits** by a social worker, occupational therapist and/or nurse. In fiscal year 2007, The ALS Association Greater New York Chapter participated in over **96** in-home visits, including wheelchair and home safety and access evaluations, helping to make the adjustments required to increase the comfort of daily life.
- **Educational programs** on research advances and patient care. In fiscal year 2007, we sponsored and organized **3** "Ask the Experts" conferences, providing patients, families, and caregivers the opportunity to meet with care experts and researchers to learn about innovative ALS treatments and research for a cure.
- **Elliot W. Dann Augmentative Communications Program.** In fiscal year 2006, The ALS Association Greater New York Chapter provided **76** assistive communication devices to **72** patients. This program helps patients find ways of communicating when speech is no longer possible by loaning communication equipment while awaiting insurance approval, or if such equipment is not covered by insurance.
- **Harold and Ruth Lopatin Transportation Program.** In fiscal year 2007, we provided over 100 rides to people for over **47** people with ALS to clinic appointments and support group meetings—people who otherwise would not have access to multi-disciplinary clinical care.
- **Jon Stone Equipment Loan Program.** In fiscal year 2007, The ALS Association Greater New York Chapter loaned **228** assistive devices and medical equipment to **178** patients to assist in maintaining the safety, comfort, and maximal functioning of the person with ALS.
- **In-service trainings for local health care professionals.** In fiscal year 2007, we conducted **5** training sessions for health care professionals to learn about the needs of ALS patients and how best to work with them.

\*The ALS Association Certified Center of Excellence

# ADVOCACY

An important aspect of The ALS Association Greater New York Chapter's work is raising awareness about ALS and advocating for legislation critical to those living with ALS.



Each spring, chapters of The ALS Association from across the country travel to Washington, D.C. for *National Advocacy Day and Public Policy Conference*. In 2006, over 700 delegates representing 43 states went to Washington to meet with their Representatives and Senators to ask for co-sponsorship of the ALS Registry Act (H.R. 4033/ S. 1353) and to allocate funding for ALS in the Department of Defense.

## **THE ALS REGISTRY ACT**

The ALS Registry Act (H.R. 4033/S. 1353) would authorize the Centers for Disease Control and Prevention to create and maintain a single nationwide ALS registry. The establishment of a national ALS registry will help identify the incidence and prevalence of ALS in the U.S. and collect data which is urgently needed for ALS research, disease management, and the development of standards of care. A national ALS registry also will promote a better understanding of the disease, help to determine causes of ALS and significantly enhance the nation's efforts to find a treatment and cure for ALS.

## **DEPARTMENT OF DEFENSE APPROPRIATIONS ACT**

Studies, including those conducted by the Department of Defense (DOD), Department of Veterans Affairs and researchers at Harvard University, repeatedly have shown that ALS occurs at a greater rate in military veterans. By including ALS in the DOD's Neurotoxin Exposure Treatment Research Program, Congress will enable important ALS research to continue at DOD, help to determine why those in the military are at a greater risk of the disease, and ensure that our nation takes appropriate action to protect the health and lives of our military men and women. Importantly, research conducted by the Department of Defense will also yield important clues and data about ALS that will benefit all people suffering from the disease and will help make progress in finding a treatment and cure for ALS.

Due to the dedication and hard work of ALS patients and their families and supporters, previous accomplishments from *National Advocacy Day* efforts include:

- Passage of the historic legislation to eliminate the 24-month Medicare waiting period for people with ALS.
- Increased annual federal funding for ALS research from \$15.1 million in 1998 to an estimated \$50 million in 2006, including funding from the National Institute of Health, the Department of Defense, and the Department of Veterans Affairs.
- Establishment of a presumptive disability ruling for ALS at the Social Security Administration, helping to ensure timely access to disability benefits for people with ALS.
- Two Congressional hearings dedicated solely to ALS, including a hearing held in 2005 by the Senate Appropriations Subcommittee on Labor and Health and Human Services. Most other diseases have not been the sole subject of a Congressional hearing, let alone two in less than five years.

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## Ryan Levine Honors Grandfather's Legacy

Ryan Levine's family is committed to finding a cure for ALS, as his grandfather, Milton Safenowitz, passed away from the disease over seven years ago. In addition to participating in the annual *Walk to D'Feet ALS*®, Ryan (front row, center) donated \$1,000 of his Bar Mitzvah money to The Greater New York Chapter in memory of his grandfather.

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## Arch Enemies of ALS

On October 23, 2006, Vincent Darragh held "Arch Enemies of ALS," a golfing event in memory of his father, Archie Darragh, who died of ALS in December of 2005. The event, held at Bellport Country Club in Bellport, Long Island, included lunch, a round of golf, a gourmet dinner and raffle prizes. "Arch Enemies of ALS," raised \$10,000 for patient services and research.



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## Make Me a Plate

On October 19, 2006, "Adding Love and Support" kicked off its first annual "Make Me a Plate" Long Island tasting event at Leonard's in Great Neck. "Make Me a Plate" raised \$85,000 for the Chapter.

"Adding Love & Support" was founded by friends and family of Barry Barkoff, a PALS, who died in 2005.

For more information about the 2nd Annual "Make Me a Plate", visit [www.addingloveandsupport.org](http://www.addingloveandsupport.org).



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WALK TO D'FEET ALS\***

*Teams "walked for"  
the people listed in italics.*

**Above \$25,000**

Anderson Walkers of Hope –  
Team Woodbridge  
*Ira Anderson*

**\$10,000 – \$24,999**

Laura's Legion of Hope  
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Rooters for Rosemarie  
*Rosemarie Sherry*

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*Robert Lewis*  
Gray Team  
Marlene's Angels  
*Marlene Welte Frachmke*  
Team Ellie  
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The Andersens Fight Back  
*Gary Andersen*  
The French Connection  
*Louis Roy*

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Amelia's Little Stars  
*Amelia Mendoza*  
D & V Legal Advertising  
*Yuet Sim Leung*  
Henry's Angels  
*Felix Marin*  
JFK Memorial High School  
*Michelle La Gasse Reggev*

Park's Pandas  
*Myong-Ja Park*

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Salfi-Gianetti

Staten Island 4 a Cure  
*Marty Cavanagh*

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*Chris Lahoda*

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*JoAnn McCormack*

Team Motz  
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Team Stanley Trela  
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Team X  
*Xavier Abbott*

The AVAs  
*Anthony Allocco*

The Man on the Door  
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XIE's Team  
*Kezhou Xie*

**To \$999**

Avenel Girls  
Beverly's Best  
*Beverly Sichel*  
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*Bill Hayes*  
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*Ruth Krieger*

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Wasser  
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*Chris Estok*

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WALK TO D'FEET ALS\*****Above \$10,000**

OPA's Crew  
*Manfred Borstelmann*

Stormin' for Norman  
*Norman Holzberg*

Surf's Up  
*Stephen Adeskavitz*

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*Joseph Pettinato*

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Fighting for the Farrells  
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*Peter Gesell, Sr.*

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*Ira Anderson*

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The Butterfly Gang  
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Walking Strong  
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Arlene's Girlfriends  
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Frankie's Flyers  
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*Natalie Settlow*

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*Richard Chrisman*

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