



**Greater New York Chapter**

1994 · 20th Anniversary · 2014

The ALS Association Greater New York Chapter

March 2014

# Monthly Update

Serving New York City, Long Island, Westchester County, Hudson Valley, and Northern & Central New Jersey

42 Broadway, Suite 1724, New York, NY 10004 • (212) 619-1400

www.ALS-NY.org • Facebook.com/ALSoFGNY • Twitter - @ALSoFGNY

## Save the Dates – 2014 Walks to Defeat ALS

- NYC: Saturday, May 3 • Long Branch, NJ: Sunday, May 18 • Saddle Brook, NJ: Sunday, June 8 • Westchester, NY: Saturday, June 14
- Somerset, NJ: Saturday, June 21 • Long Island, NY: Saturday, Sept. 20 • Hudson Valley, NY: Sunday, Oct. 19

## MARCH SUPPORT GROUPS

### NASSAU COUNTY, NY

Sunday, March 2nd – 2 to 4 pm

North Shore LIJ - Plainview Hospital

888 Old Country Rd., Plainview - Downstairs

Contact: Theresa Imperato, RN, (516) 946-5467

& Cindy Keyser-Posner, LMSW (631) 416-2767

Topic: Open Discussion

*Next month's support group meets: April 6th.*

### SUFFOLK COUNTY, NY

Tuesday, March 4th - 6 to 8 pm

Stony Brook University, Dept. of Neurology

179 N. Belle Meade Road

East Setauket, NY

Contact: Theresa Imperato, RN, (516) 946-5467

& Cindy Keyser-Posner, LMSW (631) 416-2767

Topic: Open Discussion

*Next month's support group meets: April 1st.*

### HUDSON VALLEY/FISHKILL, NY

Tuesday, March 4th - 6:30 to 8:30 pm

Ambulatory Surgery Center

Building C - 3rd Floor

200 Westage Business Center, Fishkill, NY

Contact: Helen Mayer, RN, (845) 520-0952

Topic: Open Discussion

*Next month's support group meets: April 1st.*

### NORTHERN NJ/SADDLE BROOK

Thursday, March 6th – 7 to 8:30 pm

Kessler Institute for Rehabilitation

300 Market Street, Saddle Brook, NJ

Contact: Debbie Schlossberg, LMSW

and Mary Ann Mertz, RN, (732) 710-8832

Guest speaker: Dave Goldberg, Tobii Rep.

Topic: Eye Gaze Demonstration

*Next month's support group meets: April 3rd.*

### WESTCHESTER, NY/WHITE PLAINS

Tuesday, March 11th - 6 to 8 pm

Burke Rehabilitation Center

785 Mamaroneck Avenue

Main Hospital, Bldg. 7

1st Floor, Rm G-41

White Plains, NY

Contact: Helen Mayer, RN, (845) 520-0952

Guests: Licensed Art Therapists Erika

Mayer, MS L-CAT, RYT and

Deb Brass MS, CAT-LP

Topic: Art Therapy For Patients & Caregivers

*Next month's support group meets: April 8th.*

### CENTRAL NJ/NEW BRUNSWICK

Saturday, March 15th - 1 to 3pm

Rutgers Robert Wood Johnson Medical School

Medical Education Building

Room 108A, 180 Somerset Street

Follow signs to meeting

Contact: Debbie Schlossberg, LMSW and

Mary Ann Mertz, RN (732) 710-8832

Guest speaker: Betsy Thomason, BA, RRT,

Respiratory Therapist

Topic: Respiratory Issues

*Next month's support group meets: April 12th.*

### MANHATTAN, NY

Tuesday, March 18th - 6 to 8 pm

Phillips Ambulatory Care Center (Beth Israel)

10 Union Square East (b/w 14th & 15th Sts.)

Neurology Dept., 5th Floor Conf. Room

Contact: Jody Wiesel, PhD, (917) 699-9751

Guest speaker: Gioia Cianai, PhD,

Occupational Therapist

Topic: Tools to Help Patients & Caregivers

*Next month's support group meets: April 18th.*

## TELEPHONE SUPPORT GROUPS

Patient group - every Friday from 3 to 4 pm. | Caregivers group - every Friday from 4 to 5 pm.

Contact: Sue Zimmerman, LCSW at (212) 720-3050

## Upcoming Events

**3/9 - Celebrate St. Patrick's Day!** The Chapter has been named one of the official charities of the 2nd Annual Rumson St. Patrick's Day Parade in New Jersey. For more info, contact Kristen Cocoman at (212) 720-3048.

**3/11 - Kicking off the New York City and Westchester Walks!** Calling all registered Team Captains to join us for the Walk Kick-Off and Awards Celebration. For more info, contact Sarah Pattison at (212) 720-3042

**3/16 - Team ALS will once again be Running 4 A Cure in the New York City Half Marathon!** For more info on how you can support Team ALS, call Kristen Cocoman at (212) 720-3048.

**3/26 - Volunteer Night!** Come down to the office and spend a fun night volunteering for a great cause, contact Ally Davis at (212) 720-3049. Pizza will be provided.

**Registration for the 2014  
Walk to Defeat ALS is Open!**



Walk to  
Defeat ALS®  
The ALS Association

**Visit [www.ALSWALKS.org](http://www.ALSWALKS.org) to register  
for a Walk near you this year!**



Greater New York Chapter  
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## ENROLLING IN THE NATIONAL ALS REGISTRY HELPS FIND A CURE

Efforts by advocates of The ALS Association Greater New York Chapter led New York Congressman Eliot Engel to introduce a bill that was signed into law in 2008 establishing the first-ever national patient registry of people with Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease).

Representative Engel, who lost a grandmother to ALS, said he was proud to take a lead role in establishing the National ALS Registry and thanked The ALS Association for its help.

"The registry will enhance our country's efforts to find a treatment and cure for ALS," said Rep. Engel. "It will bring new hope to thousands of patients and their families, that ALS will no longer be a death sentence."

Since the Agency for Toxic Substances and Disease Registry (ATSDR), a division of the Centers for Disease Control that runs the registry, launched the enrollment website in 2010, thousands of people with ALS from every state in the nation have taken part in what has become the largest ALS research project ever created.

The information gathered by the National ALS Registry can help researchers:

- More accurately estimate the number of new cases of ALS identified each year.
- More accurately estimate the number of people with ALS at a specific point in time.
- Better understand who gets ALS and what factors affect the disease.

This spring, we will see the first of what will now be an annual report from the registry so that scientists studying the disease can use this comprehensive data in their research into the cause, treatment and cure of ALS.

Every person with ALS who enrolls increases the power of this tool in the fight against Lou Gehrig's Disease.

ALS patients like Paul Weisman, enrolled in the National ALS Registry because he believes in the benefits the registry will bring to ALS research.

"When I first heard about it, I was shocked and surprised it wasn't started until not too long ago," he said. "I see no downside to it. If you want to find a cure, you have to localize and narrow these things down. The more we as patients do to help, the more they can help us."

Paul registered himself on the website and found the process to be easy saying it was very straightforward. "They're not asking very detailed questions. There's no need to shy away from it," he said. "It's all about helping."

Paul said that when patients enroll they help everyone with ALS. He attends the ALS Association monthly support group at Stony Brook University Hospital and helps spread the word about the Registry. "It's very important," he said "It will make a difference."

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**For more information about the National ALS Registry go to our website at [www.als-ny.org](http://www.als-ny.org), call the chapter at (212) 619-1400 or email [als@als-ny.org](mailto:als@als-ny.org). If you need help enrolling in the registry, please call Christine Dunn at (212) 720-3044.**

### Chapter Awarded 4-Star Rating



The ALS Association Greater New York Chapter was awarded a coveted 4-star rating - the highest possible rating - from Charity Navigator for sound fiscal management and a proven commitment to accountability and transparency.

We are honored to be awarded this important distinction which provides our donors with greater confidence in the charitable choices they make. Charity Navigator stated "This "exceptional" designation from Charity Navigator differentiates The ALS Association Greater New York Chapter from its peers and demonstrates to the public it is worthy of their trust."