



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

**Greater New York Chapter**

The ALS Association Greater New York Chapter

October 2013

# 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](http://www.als-ny.org)

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## OCTOBER SUPPORT GROUPS

### NASSAU COUNTY, NY

Sunday, October 6th - 2 pm 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 November 3rd.*

### SUFFOLK COUNTY, NY

Tuesday, October 1st - 6 to 8 pm  
Stony Brook University,  
Department of Neurology  
179 North Belle Meade Rd  
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 November 5th.*

### HUDSON VALLEY/FISHKILL, NY

Tuesday, October 1st - 6:30 to 8:30 pm  
Vassar Brothers Medical Mall  
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 November 5th.*

### WESTCHESTER, NY/WHITE PLAINS

Tuesday, October 8th - 6 to 8 pm  
Burke Rehabilitation Center  
785 Mamaroneck Ave., Main Hospital, Bldg. 7  
1st Floor, Conference Room G-41  
White Plains, NY  
Contact: Helen Mayer, RN, (845) 520-0952  
Guest speaker: Gioia Ciani,  
Occupational Therapist  
*Next month's support group meets November 12th.*

### NORTHERN NJ/SADDLE BROOK

Thursday, October 3rd - 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  
Topic: Open Discussion  
*Next month's support group meets November 14th.*

### MANHATTAN, NY

Tuesday, October 15th - 6 to 8 pm  
Phillips Ambulatory Care Center  
(Beth Israel), 10 Union Square East  
(b/w 14th & 15th streets)  
Neurology Dept- 5th Floor Conference Rm  
Contact: Jody Wiesel, PhD, (917) 699-9751  
Topic: Open Discussion  
*Next month's support group meets November 19th.*

### CENTRAL NJ/NEW BRUNSWICK

Saturday, October 19th - 1 to 3pm  
Robert Wood Johnson University Hospital  
Medical Education Building, Room 108A  
180 Somerset Street, follow signs to meeting  
Contact: Debbie Schlossberg, LMSW and  
Mary Ann Mertz, RN (732) 710-8832  
Topic: Open Discussion  
*Next month's support group meets November 16th.*

## TELEPHONE SUPPORT GROUPS

For caregivers and patients.

Caregivers group - every Friday from 11am to 12pm.

Patient group - every Friday from 3pm to 4pm.

Contact: Sue Zimmerman at (212) 720-3050

## NATIONAL ALS REGISTRY

This October marks the third anniversary since the National ALS Registry first began collecting data on Americans living with ALS. Just in the last year, there have been some excellent additions to the Registry.

Through the Centers for Disease Control & Prevention's Agency for Toxic Substances and Disease Registry (ATSDR), the Registry is now collecting biological samples from people living with ALS to test pilot the creation of a bio-repository that will augment the survey data currently collected. Further, patients enrolled in the Registry can now receive alerts about new clinical trials that they may qualify for, making it easier for patients to be informed about the latest research in which they can participate.

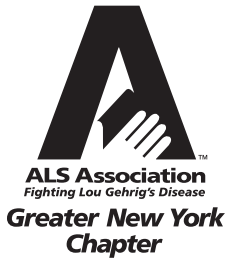
Also, for those already enrolled, there will soon be new surveys to complete later this Fall, which will better inform researchers of the behavioral and environmental factors that

may be associated with ALS. Additionally, the Registry is funding ALS research, including studies on the epidemiology of ALS, large-scale genome-wide association study of ALS, and gene-environment interactions in ALS.

In the past three years, thousands of ALS patients have self-enrolled in the Registry via a secure online web portal through the CDC - [www.cdc.gov/als](http://www.cdc.gov/als). It's easy and relatively quick.

If you require assistance with enrolling in the Registry or would like more information, please contact Christine Dunn in the Chapter office at (212) 720-3044.

Sign up at  
[www.cdc.gov/als](http://www.cdc.gov/als)



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## AMP UP YOUR GIVING: Technology Edition

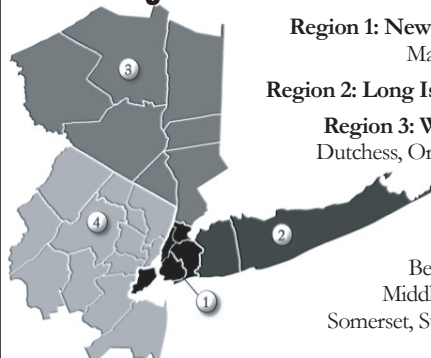
Through the generosity of numerous donors, our Chapter is able to provide our PALS with a wide array of equipment to help them maintain their independence, sustain mobility, and have the ability to communicate throughout the progression of the disease. Your gift, no matter the amount, can go a long way in helping us continue this important work for our region's PALS. Here is some of what your gift can provide:

- \$50 - Switches can give patients who have lost their ability to press on various communication devices access to an entire communication screen with one easy motion.
- \$150 - Communication Device Batteries allows our patients to be mobile and still maintain their communication. Communication systems can work while plugged in, but they become portable with the use of these batteries, fostering independence for patients and greater ease for caregivers.
- \$250 - A Voice Amplifier increases the volume of a patient with weakened or softened speech, so listeners can remain in a typical conversation space instead of staying extremely close to hear the speaker.
- \$350 - Wheelchair Batteries last about two years and provide one of the key components for a device that is critical to the movement of PALS. A power wheelchair cannot be used without a working battery, so this basic part of the wheelchair is one that is greatly needed for the Chapter.

Donate today to ensure we can continue to provide the highest quality of care to all our PALS and continue to provide the state-of-the-art equipment at no cost!

To donate or for more information, contact Loren Domilici, Development Manager at (212) 720-3060 or [ldomilici@als-ny.org](mailto:ldomilici@als-ny.org).

### Serving Patients, Families and Caregivers Throughout Greater New York and New Jersey



**Region 1: New York City.** The Bronx, Brooklyn, Manhattan, Queens, & Staten Island.

**Region 2: Long Island,** Nassau & Suffolk Counties.

**Region 3: Westchester and Hudson Valley.** Dutchess, Orange, Putnam, Rockland, Sullivan, Ulster, & Westchester Counties.

**Region 4: Northern & Central New Jersey**

Bergen, Essex, Hudson, Hunterdon, Middlesex, Monmouth, Morris, Passaic, Somerset, Sussex, Union, & Warren Counties.

To find the Patient Care Services representative in your area, call (212) 619-1400 or toll free at (800) 672-8857.

**Fighting ALS from your Desk:** Through employee giving programs, you can dedicate pre-tax money to our Chapter to help support research and people living with ALS in our community. To designate our Chapter, use the following codes:

Combined Federal Campaign (CFC): 56276 | State Employees Federated Appeal (SEFA): 99900019 | Combined Municipal Campaign (CMC): 1741 | United Way: The ALS Association Greater New York Chapter

### Upcoming Events

**10/10 - Young Professionals Group monthly meeting.** For more information please contact Loren Domilici at [ldomilici@als-ny.org](mailto:ldomilici@als-ny.org) or (212) 720-3060.

**10/20 - Hudson Valley Walk to Defeat ALS, Highland, NY.** Contact Sarah Pattison at (212) 720-3042 or [spattison@als-ny.org](mailto:spattison@als-ny.org) for details.

**10/25 - Young Professionals Group Fall Fundraiser** at Maxwell's, 59 Reade Street, Manhattan. Contact Loren Domilici at [ldomilici@als-ny.org](mailto:ldomilici@als-ny.org) or (212) 720-3060 for details.

**11/3 - ING New York City Marathon - GO Team ALS!** Please contact Kristen Cocoman at [cocoman@als-ny.org](mailto:cocoman@als-ny.org) or (212) 720-3048 for more info.