



ALS Association
Fighting Lou Gehrig's Disease

**Greater New York
Chapter**

The ALS Association Greater New York Chapter

August 2012

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

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August Support Groups

SADDLE BROOK / NORTHERN NJ

Thursday, August 2nd - 7 pm to 8:30 pm
Kessler Institute for Rehabilitation
300 Market St., Saddle Brook, NJ
Topic: Open Discussion
Contact: Debbie Schlossberg, LMSW (732) 710-8832

NASSAU COUNTY, NY

Sunday, August 5th - 2 pm to 4 pm
North Shore LIJ - Plainview Hospital
888 Old Country Road, Plainview - Downstairs
Speaker: Kristen Cocoman, Walk to Defeat ALS
Contact: Theresa Imperato, RN, (516) 946-5467 and
Jody Wiesel, PhD (917) 699-9751

SUFFOLK COUNTY, NY

Tuesday, August 7th - 6 pm to 8 pm
Stony Brook University, Dept. of Neurology
179 North Belle Meade Rd, E. Setauket
Speaker: Kristen Cocoman, Walk to Defeat ALS
Contact: Theresa Imperato, RN, (516) 946-5467

HUDSON VALLEY, NY

Tuesday, August 7th - 6:30 pm to 8:30 pm
Vassar Brothers Medical Mall
Ambulatory Surgery Center - Bldg C - 3rd Floor
200 Westage Business Center, Fishkill, NY
Speaker: Gioia Ciani, Occupational Therapist, Beth Israel
Massage Therapist Max Cohn will be donating massages.
Contact: Helen Mayer, RN, (845) 520-0952

NEW BRUNSWICK / CENTRAL NJ

Saturday, August 18th - 1 pm to 3 pm
Robert Wood Johnson University Hospital
Medical Education Building, Rm. 108A
180 Somerset Street, follow signs to meeting
Topic: Social Security and Medicare
Speaker: SHIP (Senior Health Insurance Program)
Contact: Debbie Schlossberg, LMSW and
Mary Ann Mertz, RN, (732) 710-8832

MANHATTAN, NY

Tuesday, August 21st - 6 pm to 8 pm
Phillips Ambulatory Care Center (Beth Israel)
10 Union Square East (b/w 14th & 15th streets)
Neurology Dept- 5th Floor Conference Room
Guest: Wendy Henry, Acupuncturist
Contact: Jody Wiesel, PhD, (917) 699-9751

TELEPHONE SUPPORT GROUPS

Caregivers: Fridays - 11 am to 12 pm
Patients: Fridays - 3 pm to 4 pm
Contact: Sue Zimmerman at (212) 720-3050

Note: June through September, telephone support groups will occur bi-weekly, with this month's meetings occurring on August 3, 17 & 31.

Making a Difference *by Cynthia Pallotto*

I've had the privilege of volunteering for the ALS Association Greater New York Chapter for the past year and I want to share my reasons for devoting time to this organization and the impact it has had on my life.

Over 18 years ago, I found myself to be the daughter of a mother who was diagnosed and later passed away from ALS. I worked endlessly to find medical information and resources for my family. There was very little available at that time. As an adult child of an ALS patient and a caregiver, the one outlet I was able to participate in was a much-needed support group. Here, for a time, I could connect with those who were also in this devastating situation and could understand the day-to-day navigation of this disease's awful course. Led by clinical service personnel, working in tangent with the ALS Association, I found comfort and a respite when at times I felt like I was drowning. It was my lifeline at that time and I made a promise that if the situation presented itself, and if I had the opportunity, I would offer my services to give back to the Association in some way.

I knew of the ALS Association Greater NY Chapter from my monetary donations through the years since my Mother's passing. The Chapter had not been in existence when she was ill, but I was now aware of the work they were doing and their bringing ALS awareness and education to the New York/New Jersey region.

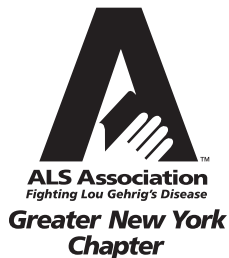
I reached out to the Chapter when I found myself suddenly unemployed after over 30 years in the entertainment advertising industry. I came from a business world of much material excess, trivial spending and little gratification in my daily work life. That all changed when I came to volunteer in the New York office. With one simple email and a quick one-on-one meeting, I was able to work out a weekly schedule and offer my services to various departments of the chapter and I was welcomed with open arms.

Here I could make a difference in doing very simple assignments and find gratification in working for a worthwhile cause. Whether my help was needed in facilitating donation mailings, composing thank you letters, or inputting data, it all led to support and care for patients living with ALS and their families. Working alongside individuals who give their all to raise funds and find a cure for ALS, I have found a new purpose for my skills and an appreciation for being a part of a team who actually makes a difference.

The Chapter provides answers, support, and most of all compassion when it is needed the most. I cannot state more emphatically my support for this great organization and their work and highly endorse them as a recipient of your time and generosity.

I can guarantee, that if you decide to volunteer as I have, you will be well rewarded just by knowing that even the smallest office tasks are taking a step towards finding a cure for this disease and making a positive impact on people's lives.

Want to volunteer? If you live in New York, contact Christine Dunn at (212) 720-3044 or dunn@als-ny.org. In New Jersey, contact Debbie Schlossberg at (732) 710-8832 or schlossberg@als-ny.org.



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42 Broadway, Suite 1724
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Take Me Out to the Ballgame

On July 2nd the Greater NY Chapter headed to Coney Island, home of the Brooklyn Cyclones to kick-off a series of ALS Awareness Nights with our area Minor League Baseball teams. Brooklyn native and PALS Adrian Dessi was on-hand with his family to throw out the first pitch. The evening was filled with peanuts, popcorn & ALS awareness. A great time was had by all... and the Cyclones won in extra innings!



National Grid to Add nationalgrid Bling to the Walk

The Olympic Games isn't the only place seeing GOLD right now! The Chapter is happy to announce that National Grid has signed on as a new Gold Sponsor for the 2012 Long Island Walk to Defeat ALS! National Grid is a leading energy company in the Northeast United States, providing light and warmth to millions of homes and power to factories and businesses. Special thanks to our Honorary LI Walk Chair, Bob Catell, former National Grid USA Executive Chairman and to LI Walk co-chair, Michael Ruiz, National Grid Downstate Director. We are so excited to partner with National Grid and look forward to working with their team during the Fall Walk Season. Thank you for your support.

Long Island Strong!



2012 Walk Sponsor and Long Island Accounting Firm, Cullen & Danowski, LLP, is Long Island's new powerhouse corporate team! Cullen's Crusaders was formed in honor of the firm's partner, Vinnie Cullen, a newly diagnosed PALS. In just over six months, "Cullen's Crusaders" have registered over 130 Walkers and have raised nearly \$60,000!

Register for a Walk to Defeat ALS near you!

Long Island Saturday, Sept. 29 | Eisenhower Park, East Meadow
Hudson Valley Sunday, Oct. 21 | Walkway over the Hudson
For more information go to: www.alswalks.org

@sk Ben...

My mother lives with us. She has her own room and even a communication device, but the device is not always near her and it is not always turned on. Do you have any advice on a simple way for her to get our attention while in the house?

- Ellen, Dutchess County, NY

There are definitely some relatively easy and cost conscience ways to solve this problem. There are buzzers and bells which can be activated with a certain level of hand control. However, the sound will likely only be audible from the same general vicinity, and may not be heard in another part of the house. You may also want to consider a wireless door bell. The small button that is normally attached outside the door, can be placed anywhere in the home - a wheelchair, bed, or your lap. The bell can then be placed in a central location in the home. Some models come with two activating buttons so one could be by the chair and another by the bed.

Since some finger control is necessary, you may want a 'switch adapted door chime'. These allow a switch to be attached to the button to make it easier to activate. The switch is a separate purchase, but can be placed where you are able to move even if just minimally (i.e. near a toe, behind the head on the wheelchair, or under a finger).

Prices for wireless door bells are generally under \$50. They can be found in home supply or electronic stores, and online. Switch adapted doorbell could cost around \$100.

- Ben

To ask Ben a question, simply email him at blieman@als-ny.org or call at (212) 720-3057. Ben will answer all questions directly as usual, but not all questions will appear in the Monthly Update.