



ALS Association
Fighting Lou Gehrig's Disease

**Greater New York
Chapter**

The ALS Association Greater New York Chapter

December 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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December Support Groups

*Topic for all groups this month
will be Holiday Celebration!*

HUDSON VALLEY, NY

Tuesday, December 4th - 6:30 pm to 8:30 pm
Vassar Brothers Medical Mall
Ambulatory Surgery Center - Bldg C - 3rd Floor
200 Westage Business Center, Fishkill, NY
Contact: Helen Mayer, RN, (845) 520-0952

SADDLE BROOK / NORTHERN NJ

Thursday, December 6th - 7 pm to 8:30 pm
Kessler Institute for Rehabilitation
300 Market St., Saddle Brook, NJ
Contact: Debbie Schlossberg, LMSW and
Mary Ann Mertz, RN, (732) 710-8832

NEW BRUNSWICK / CENTRAL NJ

Date Change for December.

Saturday, December 8th - 1 pm to 3 pm
Robert Wood Johnson University Hospital
Medical Education Building, Rm. 108A
180 Somerset Street, follow signs to meeting
Contact: Debbie Schlossberg, LMSW and
Mary Ann Mertz, RN, (732) 710-8832

NASSAU COUNTY, NY

Date Change for December.

Sunday, December 9th - 2 pm to 4 pm
North Shore LIJ - Plainview Hospital
888 Old Country Road, Plainview - Downstairs
Contact: Theresa Imperato, RN, (516) 946-5467
and Jody Wiesel, PhD (917) 699-9751

SUFFOLK COUNTY, NY

Date Change for December.

Tuesday, December 11th - 6 pm to 8 pm
Stony Brook University, Dept. of Neurology
179 North Belle Meade Rd, E. Setauket
Contact: Theresa Imperato, RN, (516) 946-5467

MANHATTAN, NY

Tuesday, December 18th - 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
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

A Holiday Message from the President & CEO

The holiday season is upon us again and we take this time to give thanks and to reflect back on 2012... an extraordinary year for our Chapter. I'd like to highlight a few of our accomplishments:

Patient service is a core part of our Chapter's mission. We now serve nearly 700 patients and families in New York and New Jersey. In the last year, we expanded our service area to include five new counties in the Hudson Valley Region. We hired two additional nurses to conduct home visits and, we added our third equipment loan closet.

We were delighted to announce our newest partnership with one of the premiere medical institutions in our city - the Hospital for Special Surgery. We established a new ALS Association Program at the hospital to provide multidisciplinary care to people with ALS.

We continue to provide state-of-the-art multidisciplinary care at our three ALS Association Certified Centers of Excellence - Beth Israel Medical Center, Robert Wood Johnson University Hospital and Stony Brook University Hospital.

Building greater public awareness and support is essential to winning the fight against Lou Gehrig's Disease. This year, the Greater New York Chapter sponsored six "Walks to Defeat ALS."

Nearly 12,000 people participated in these walks, helping to raise almost \$2 million to benefit ALS research and services.

In May, ALS Awareness Month, Chapter advocates travelled to Washington, DC for National ALS Advocacy Day, reaching out to an unprecedented number of lawmakers on Capitol Hill. We also rang the closing bell at the New York Stock Exchange, which garnered nationwide attention to our cause.

Our partnerships with Major League Baseball and Minor League Baseball continue to bring attention to Lou Gehrig's disease and to military veterans living with the disease. The Young Professionals Group continues to expand, bringing vitality and renewed enthusiasm to all of our Chapter's efforts.

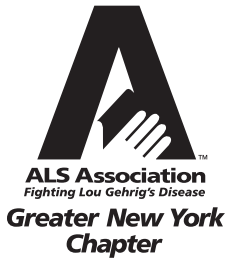
Achieving our vision of a world without ALS requires a tremendous investment in research.

I'm proud to report that since our founding our Chapter has funded over \$7 million to find effective treatments and a cure for Lou Gehrig's Disease. As part of that effort, we've supported a number of important ALS research projects in our own back yard which bring us closer to developing effective treatments for ALS.

A month ago our region experienced one of the worst natural disasters to befall our area in decades. We were fortunate that our PALS were safe and our supporters were generous with their donations allowing our services to continue unabated during this crisis. Thanksgiving is now passed, but it's never too late to express our gratitude to all of our volunteers, donors, advocates, caregivers, and most of all - our PALS. You are the heart & soul of this organization and it is a privilege to fight ALS alongside of you.

On behalf of the entire Board and Staff of The ALS Association Greater New York Chapter, I wish you the Happiest of Holidays & a peaceful New Year.

Sincerely,
Dorine Gordon



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Research Begins with You

By Dorothy Smith - Edison, NJ

My name is Dorothy Smith and I was diagnosed with Amyotrophic Lateral Sclerosis (ALS) in June 2010. I would like to share with you my recent experience with the Northeast ALS Consortium (NEALS), and specifically my attendance at the 2nd Annual ALS Clinical Research Learning Institute (CRLI) in Clearwater, Florida in late October. But first let me tell you a bit about myself.

I am a wife, mother and grandmother. Prior to my diagnosis, I had a rewarding career, with a daily two hour commute to Manhattan. I am now confined to a wheelchair. With a life expectancy of two to five years for an ALS patient, it is essential that I share my experience with you and encourage you to help find a cure, while I still have time. I participated in one research study for almost two years. That study has ended, with results to be published this month. I am now actively seeking another study in which to participate. Even if it does not prolong my life expectancy, it keeps me active, interested and in a positive frame of mind.

NEALS is a non-profit organization dedicated to translating scientific advances into new treatments for people with ALS. NEALS functions as an academic research consortium, a contracted research organization, and a resource tool for the ALS community. Please visit their website at alsconsortium.org for the latest research information.

In the spring of 2012, the Chief Neurologists of the ALS clinics were asked to submit proposals for candidates to be ALS Research Ambassadors. My physician, Dr. Jerome Belsh, Medical Director of the ALS Association Center of Excellence at Robert Wood Johnson University Hospital, nominated my husband and me and we were subsequently selected to participate.

The goal was to teach the attendees about the research process and trial design, how to critique a scientific publication, the ALS study pipeline, barriers to success and how to overcome these barriers. It was also an opportunity to meet and speak with key researchers and active PALS from all over the country.

To read the entirety of the article go to www.als-ny.org.

Season of Giving, Season of Hope

Our Chapter is proud to provide comprehensive services to people with ALS (PALS) throughout the year. These services are instrumental in our fight because ALS never takes a holiday. To continue our efforts, we need your help. Your gift will help support:

- Patient and Family Services for people living with ALS and their families throughout the Greater New York area.
- Research designed to speed therapy development by addressing ALS on all fronts, from basic research to clinical trials.
- Advocacy to increase government funding of research and sponsorship of legislation to make treatments and care accessible and affordable for all PALS.

Your donation allows us to be the constant and reliable support system our PALS and their families need while battling this disease. During this time of giving, please consider making a donation to support our efforts in fighting ALS and finding a cure.

All donations made on or before Dec. 31st are tax deductible for 2012. To donate, contact Loren Domilici at (212) 720-3060.