



The ALS Association Greater New York Chapter February 2009

Monthly Update

ALS Association
Fighting Lou Gehrig's Disease

Serving Greater New York and Northern and Central New Jersey
116 John Street, Suite 1304, New York, NY 10038, 800-672-8857 f: 212-619-7409 www.als-ny.org

February Support Groups

NASSAU COUNTY, NY

February 1, 2009 2:00-4:00 PM
(1st Sunday of every month)
North Shore's Central General Hospital
888 Old Country Road, Plainview
Downstairs Meeting Room; (516) 719-3000

Topic: TBD

Facilitators: Theresa Imperato, RN - (631) 444-4623
Jody Wiesel, PhD - (917) 699-9751

SUFFOLK COUNTY, NY

February 3, 2009 6:00-8:00 PM
(1st Tuesday of every month)
Stony Brook University, Dept. of Neurology
179 Belle Meade Rd, E. Setauket
(631) 444-1970

Topic: TBD

Facilitator: Theresa Imperato, RN - (631) 444-4623

MANHATTAN, NY

February 17, 2009 6:00-8:00 PM
(3rd Tuesday of every month)
Phillips Ambulatory Care Center (Beth Israel)
10 Union Square East (Bet. 14th & 15th St.)
2nd Floor, Conference Room #1

Topic: Open

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

NEW BRUNSWICK, NJ

February 21, 2009 1:00-3:00 PM
(3rd Saturday of every month)
Robert Wood Johnson University Hospital
Medical Education Building, Rm 108A
180 Somerset Street, Follow signs to meeting.

Topic: Travel

Speaker: Representative of SATH
(Society for Accessible Travel and Hospitality)

Facilitator: Debbie Schlossberg, LMSW
(732) 710-8832
Mary Ann Mertz, RN

For more information about our Support Groups:
Goto the Patient Services section at
www.als-ny.org or call 800-672-8857.

**PLEASE NOTE: THE ALS ASSOCIATION GREATER NEW YORK CHAPTER IS MOVING OFFICES AT THE END OF JANUARY. OUR NEW ADDRESS WILL BE:
42 BROADWAY, SUITE 1724, NEW YORK, NY 10004**

GREATER NEW YORK CHAPTER STAFF INVITED TO SPEAK AT NATIONAL LEADERSHIP CONFERENCE

The ALS Association Greater New York Chapter is proud to announce that four of our staff members were selected to present in five separate sessions at the National Leadership Conference held annually by the ALS Association. The Conference is designed to gather together members from ALS Association Chapters from around the country so they can share ideas, successes and information to learn to better service patients, raise funds and work toward a cure for ALS.

Theresa Imperato, R.N. is our Nurse Coordinator for the ALS Clinic at Stony Brook Medical Center on Long Island. She will co-present in the Clinical Track, "The Nuts and Bolts of ALS." Her session provides foundational information for national chapter attendees who are new to ALS.

Theresa will also be presenting "Sealing the Deal: Encouraging Tube Feeding in Patients with ALS." Theresa will be joined by Lorraine Danowski, MSRD, our Nutritionist at the Stony Brook ALS Clinic. During the session Theresa and Lorraine will provide important information for members of the multi-disciplinary ALS teams at clinics across the country.

Debbie Schlossberg, LMSW, our Patient Services Coordinator at the Robert Wood Johnson Medical Center ALS Clinic, will join Theresa to inform Chapter members about "Helping Hospices Understand Treatment Issues for ALS Patients."

Our staff Assistive Technologist, Antoinette Verdone, MSBME, ATP, will be co-presenting an advanced session on Managing an Assistive Technology Loan Program, addressing the complex issues and challenges that come along with the job for ALS Chapters nationwide.

As well, with her extensive experience in the field, Antoinette was selected to be the sole presenter of an important topic to members titled, "Durable Medical Equipment Loan Programs: How To's and Lessons Learned."

We are proud of all the work our staff members do everyday, but we are especially happy that these select members of the The ALS Association Greater New York Chapter family are able to share their exceptional skills with our sister Chapters to improve the lives of ALS patients nationwide.

The NY Chapter has a Lending Library available to all PALS.
We have books on CD or audio tape. If you would like to borrow books please contact Christine Dunn at the Chapter office or e/mail dunn@als-ny.org.





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First-Class Mail
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VOLUNTEER NIGHT February 19, 2009 5-7 PM. Contact Christine @ 212-720-3044

CALENDAR of EVENTS

02/14/09 - Valentine's Day Dinner To Benefit ALS, Wall's Wharf, 18 Greenwich Avenue, Bayville, NY, Call Luke at 516-628-9696 for Reservations.

02/27/09 - 3rd Annual Big Ed Benefit IMO Ed Flanagan, Metro 53, 307 East 53rd Street, bet. 1st & 2nd Avenues, New York, NY, 5:30 PM to 9:00 PM, \$60 Per Person. Open Bar.

If you haven't been there lately, check out what's new on our website, www.als-ny.org

PLEASE GIVE!

Leave A Legacy of Hope



CHARITABLE GIFT ANNUITY

A gift annuity is a simple contract between you and **The ALS Association Greater New York Chapter**. In exchange for your gift of cash or stock, The ALS Association Greater New York Chapter makes regular payments to you, you and your spouse or someone you name, for life. The remaining principal goes to The ALS Association Greater New York Chapter when the contract ends.

For information please call
Beth Mohsinger at (212) 720-3060
or email: mohsinger@als-ny.org

FOCUS ON

Fern Cohen: Blogging to Spread ALS Awareness

Fern Cohen has learned that spreading ALS awareness happens on a daily basis. Patience and a willingness to be open about her disease are most important. Says Fern, "Most people have never met someone with ALS, and only know it from Lou Gehrig."

By writing a blog, Fern welcomes people to take a peek at living with ALS. Here she discusses clinic visits, dealing with aides and how she copes with feelings of solitude.

In her blog she describes herself and her motivation to write: I live in Queens, NYC with my foster bunny Chelsea. I am a product of Depression-era parents, who brought me up with good, wholesome middle-class Jewish values, on a steady diet of Chinese food and non-cable TV. All things considered, I came out okay, except that I am neurologically disabled since 2004, when I was diagnosed with ALS/Lou Gehrig's Disease. This caused me to finally "sit still and shut up", something people have been begging me to do all

my life. So I write. The rest is history.

In one very gratifying encounter, Fern wrote in one of her posts that at the ALS meeting/holiday party at Beth Israel Medical Center, she was approached by the mother of a patient who said they "learned from my blog about the accessible taxi dispatch program, and tried it because their wheelchair van is in repair." They had a generally favorable experience but the point is that people are reading and getting something valuable out of her blog.

Fern has even embraced Twitter, the micro-blogging platform that's gaining popularity. From her account at Twitter.com/ferncohen she talks about updates to her blog and other related news of interest, all in 140 characters or less, which is the word limit of Twitter posts, sometimes called Tweets. The Chapter currently is working with Fern to help form the chapter's first ever online Support Group Meeting using Twitter.

Find Fern Cohen online at www.fernals.blogspot.com or read her blog on being a Baby Boomer www.ferncohen.blogspot.com
Fern's Twitter profile is at www.twitter.com/fec139