



ALS Association
Fighting Lou Gehrig's Disease

**Greater New York
Chapter**

The ALS Association Greater New York Chapter

March 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

March Support Groups

SADDLE BROOK / NORTHERN NJ

Thursday, March 1st - 7 pm to 8:30 pm
Kessler Institute for Rehabilitation
300 Market St., Saddle Brook, NJ
Contact: Debbie Schlossberg, LMSW (732) 710-8832

NASSAU COUNTY, NY

Sunday, March 4th - 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

Tuesday, March 6th - 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

HUDSON VALLEY, NY

Tuesday, March 6th - 6:30 pm to 8:30 pm
Ambulatory Surgery Center - Bldg C - 3rd floor
200 Westage Business Center, Fishkill, NY
Massage Therapist Max Cohn will be onsite donating
massages for both CALS and PALS
Contact: Helen Mayer, RN, (845) 520-0952

NEW BRUNSWICK / CENTRAL NJ

Saturday, March 17th - 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

MANHATTAN, NY

Tuesday, March 20th - 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: Wednesdays - 11 am - 12 pm
Patients: Wednesdays - 3 pm - 4 pm
Adult children of PALS: Friday - 11 am - 12 pm
Contact: Sue Zimmerman at (212) 720-3050

**The discussion topic for all Support Groups
for the month of March is open.**



You are cordially invited
to attend the 2012 National
ALS Advocacy Day & Public
Policy Conference in
Washington, DC on May 13-15!

These are exciting times in ALS research. Scientists have made groundbreaking discoveries in the past year that have greatly increased our understanding of the disease and provided new opportunities to treat it. At the same time, several promising clinical trials are underway that could result in the first new treatments for ALS since 1995. These breakthroughs and opportunities did not occur by chance. They happened in part because the federal government provided the resources and the environment necessary to make advances in ALS research possible.

National ALS Advocacy Day gives us the opportunity not only to continue the progress that has been made, but also opens up exciting new pathways to incentivize and accelerate the discovery of the cause, treatment and cure for ALS.

Your participation is critical! Without it, the progress we have realized may not continue and the fight against ALS may fall victim to politics and budget cuts. You have made a difference through advocacy. And your help is needed now more than ever. So please join us in Washington and help us continue to create the roadmap that will lead to a treatment and cure for Lou Gehrig's Disease.

For more information on Advocacy Day or to attend, please contact Daryl Cochrane at (212) 720-3051 or at dcochrane@als-ny.org.

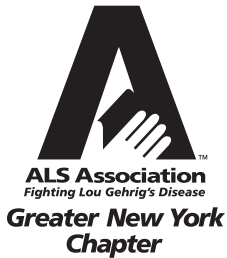
Childrens & Teens Day - Saturday, April 14th

Read the Monthly Update online for more details
or call Stacy De Witt at (212) 720-3053.

In Need of Help?

If you are a patient, caregiver, or family member and need a little help to lighten your work load please contact us and we will request a volunteer for you. Volunteers can help in many ways - from walking your dog, shopping, or just reading aloud.

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



Greater New York Chapter
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f: 212-619-7409
www.als-ny.org

Going to the Doctor: Getting There is Half the Battle

Getting to your doctor's appointment should be simple. But, for many patients living with ALS it isn't so easy.

Vincent Darragh knows first-hand how hard it can be. His father, Archie, was a big guy with a huge heart and quickly became a key member of the Chapter's Stony Brook support group. However, as ALS began to take a toll on his body, it became increasingly difficult to get to his ALSA Clinic.



(L to R) Theresa Imperato, RN, Nurse Coordinator at ALS Association Center at Stony Brook, Vincent's mom, Joan Darragh, Vincent Darragh.

According to Vincent, his father "loved going to Stony Brook. He was a big guy and my mother had a hard time lifting him." That's when he and his friends decided to hold a golf tournament to raise money for the Chapter's Transportation Program.

"We wanted people to get their ALSA appointments," said Vincent. In the years that followed Archie's death in 2005, the Darragh family team, "Arch Enemies of ALS," has raised over \$50,000.

"The services provided by the clinic are wonderful, but if you can't get to them, that's a real problem for one's health," said Vincent.

The Chapter provides transportation free-of-charge to patients who have no other means of getting to their appointments at our ALS Centers at Beth Israel Medical Center, Stony Brook University Hospital, Robert Wood Johnson University Hospital, or the Hospital for Special Surgery.

To learn more about the Greater New York Chapter's Transportation Program, contact Christine Dunn at (212) 720-3044.

Handrails - Function over Form

The ability to move around one's own home – the simple activity of going from the bedroom to the bathroom to the living room and to the kitchen is a basic task that an ALS patient loses as the disease progresses. Whereas stairs before were a gateway to an expansive dwelling, as strength and balance diminish, they quickly become an impediment that needs careful maneuvering.

Handrails can help meet the challenge. When a person is only able to walk slowly or with minor assistance, a handrail can help get them around their home, even in a hallway.

Following are some helpful handrail basics:

Grasp-ability - Handrails should be:

- 1 1/4" - 1 1/2" in diameter. Round is most popular, though some studies suggest that a long notch for fingers to grab along the sides, enable a better grip.
- No closer to the wall than 1 1/2" (Enabling even a large hand to grasp the handrail securely, and avoid fingers and knuckles scraping the wall.
- Placed at a height of 34"-38" off the step, and continue past the step a minimum of 1/2 the width of the step. This assures having something to hold onto before and after the stairs.
- Placed on both sides of a stairway or hallway, for use with both hands or the stronger hand.

To read our full article on Handrails please go to our website at www.als-ny.org.

If you would like more information about this or other home modification ideas, please contact Ben Lieman at (212) 720-3057.