



ALS Association
Fighting Lou Gehrig's Disease

**Greater New York
Chapter**

The ALS Association Greater New York Chapter

August 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

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AUGUST SUPPORT GROUPS

NORTHERN NJ/SADDLE BROOK

Thursday, August 1st - 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
Topic: Open Discussion

NASSAU COUNTY, NY

Sunday, August 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 Cindy Keyser-Posner, LMSW (631) 416-2767
Topic: Long Island Walk to Defeat ALS
Guest Speaker: Kristen Cocoman, Greater NY Chapter

SUFFOLK COUNTY, NY

Tuesday, August 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
and Cindy Keyser-Posner, LMSW (631) 416-2767
Topic: Long Island Walk to Defeat ALS
Guest Speaker: Kristen Cocoman, Greater NY Chapter

HUDSON VALLEY, NY

Tuesday, August 6th - 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
Topic: Open Discussion

WESTCHESTER, NY/WHITE PLAINS

Tuesday, August 13th - 6 pm to 8 pm
Burke Rehabilitation Center
785 Mamaroneck Avenue
Main Hospital, Bldg. 7, 1st Floor
Conference Room G-41, White Plains, NY
Contact: Helen Mayer, RN, (845) 520-0952
Speaker: Ben Lieman, Assistive Technologist,
Greater NY Chapter

CENTRAL NJ/NEW BRUNSWICK

Saturday, August 17th - 1pm 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

Upcoming Events

8/7 - Young Professionals Group monthly meeting. Contact Loren Domilici for details at ldomilici@als-ny.org or (212) 720-3060.

8/11 - ALS Awareness Day with Minor League Baseball's Staten Island Yankees. Contact Kristen Cocoman for info or to RSVP at cocoman@als-ny.org or (212) 720-3048.

8/25 - Children & Teens Day (New York City) For kids 8-18 years old who've lost a loved one to ALS, at Little Shop of Crafts. For additional information, or to register your children, please contact Susan Zimmerman, LCSW at (212) 720-3050.

8/31 - ALS Awareness Day with Minor League Baseball's Hudson Valley Renegades. Contact Kristen Cocoman for info or to RSVP, at cocoman@als-ny.org or (212) 720-3048.

Keep Walking to Defeat ALS

It's not too early to register for one of our two remaining Walks to Defeat ALS this Fall!

- On Sunday, September 22nd, join us at the largest Walk in the country – the Long Island Walk to Defeat ALS at Eisenhower Park in East Meadow, NY. More than 5,000 people from throughout the region will come together to do their part to raise funds and awareness in hopes of creating a world without Lou Gehrig's Disease.

- On Sunday, October 20th, the Chapter hosts one of the most scenic Walks to Defeat ALS nationwide. Enjoy the beautiful Fall foliage along the banks of the Hudson River, as we traverse the Walkway Over the Hudson in Highland, NY, in the heart of the Hudson Valley.

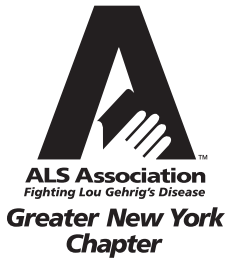
Both Walks offer a great day for the entire family, including music, activities for children, food, team mascots, and entertainment. You can also get more information on the Chapter's services for people with ALS and caregivers and find more ways to get involved in the local ALS community year-round. Visit our website at www.alswalks.org to sign up!

MANHATTAN, NY

Tuesday, August 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
Topic: Open Discussion

TELEPHONE SUPPORT GROUPS

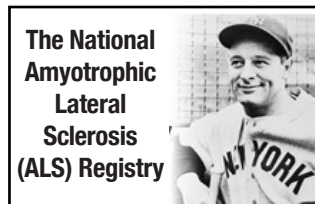
For caregivers and patients. Summer schedule: will be held on a bi-weekly basis: 7/26, 8/9, 8/23, 9/6, 9/20. Contact: Sue Zimmerman at (212) 720-3050



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www.als-ny.org

Are You Signed Up For The ALS Registry?

If you're a PALS (Person with ALS), you should know about the National ALS Registry. Many have already enrolled, but if you haven't, we hope you'll take these remaining summer months to do so.



The National ALS Registry is a program begun by Congress and run through the Centers for Disease Control and Prevention to collect, manage, and analyze data about PALS. The more people enrolled with the Registry, the more data will be collected, and the more accurate the information will be for researchers to analyze specific areas on which to focus, that could lead to an effective treatment and eventual cure for ALS.

How do you enroll? If you have a computer, it is easy to enroll with the National ALS Registry. A PALS, with the help of a caregiver if needed, can visit www.cdc.gov/ALS to get started. Questions will be asked about health, job, family history, military service. Initial enrollment could take 10-20 minutes and filling out additional survey could take as little as an hour. All the information collected is confidential, with only researchers of the CDC's Agency for Toxic Substances and Disease Registry (ATSDR) able to access that information, which would not have names along with it.

While the National ALS Registry works to provide information for researchers, it also is there to help you not only contribute amazing awareness for the disease,

but to additionally provide opportunities for you to participate in clinical trials. New features in the last year allow PALS to contribute to a biorepository which collects samples of hair, blood, nails, and other resources that will provide researchers with even more data to identify the disease's commonalities.

Hear what three area PALS who've already enrolled, have to say about their experience:

"I will do anything I can do to find a cure for this condition. People came and took hair, nail, and blood samples. It was easy, plus it's been good to touch base with others about the disease." - Jane B., Ho Ho Kus, NJ

"I registered to try to raise awareness of the disease so people in Washington will understand and hopefully they'll work toward moving drugs along faster so we can someday cure ALS. They need to change their research methodology and this can help." - Michael Z., Wayne, NJ

"The Registry was very helpful with their resources and knowledge. I think this will spread more awareness and help, that they'll start to find the cure. I also don't feel alone in my hope." - April S., Walden, NY

If you have questions about the National ALS Registry, please contact Manager of Communications & Public Policy Daryl Cochrane at (212) 720-3051 for assistance. Knowledge is power and with your help we can find a cure for ALS.