



ALS Association
Fighting Lou Gehrig's Disease

**Greater New York
Chapter**

The ALS Association Greater New York Chapter

June 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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2013 Spring Walks to Defeat ALS: Saddle Brook, NJ - June 9 • Bridgewater, NJ - June 15 • Westchester, NY - June 23 - www.alswalks.org

JUNE SUPPORT GROUPS

NASSAU COUNTY, NY

Sunday, June 2nd - 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: Respiratory Issues in ALS patients - new
procedure: Diaphragm Pacing System.
Guest Speaker: Dana A. Telem, MD

SUFFOLK COUNTY, NY

Tuesday, June 4th - 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: Respiratory Issues in ALS patients - new
procedure: Diaphragm Pacing System.
Guest Speaker: Dana A. Telem, MD

HUDSON VALLEY, NY

Tuesday, June 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
Topic: Coping Skills & Open Discussion
Speaker: Jody Wiesel, PhD

SADDLE BROOK / NORTHERN NJ

Thursday, June 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
Topic: Respiratory Issues/Care for ALS patients
Guest Speaker: Dr. Philip Schiffman

NEW - WHITE PLAINS/WESTCHESTER, NY

Tuesday, June 11th - 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
Topic: Open Discussion & Introductions

MANHATTAN, NY

Tuesday, June 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
Topic: : Open Discussion, "Coping with ALS"

NEW ALS Support Group - Westchester County, NY

The ALS Association Greater New York Chapter is proud to announce its newest monthly support group - in Westchester County. With the addition of this group, the Chapter now holds seven support groups each month throughout New York and New Jersey. Our support groups allow patients, caregivers and other loved ones to share their thoughts and feelings in a safe and confidential environment with other people impacted by ALS. Each month we enlist experts in various disciplines and allow for frank, open discussion, which can provide emotional and practical support.

Our first Westchester support group will meet on Tuesday, June 11th from 6:00pm-8:00pm at the Burke Rehabilitation Center located at 785 Mamaroneck Avenue; Main Hospital, Building 7, First Floor, Conference Room G-41 in White Plains, New York. We will continue to meet at this time and place on the second Tuesday of each month. For more information, call Patient Services Coordinator Helen Mayer, RN at (845) 520-0952.

We look forward to seeing you on June 11th in Westchester or at one of our other 6 monthly groups!

Upcoming Events

6/9 - Saddle Brook, NJ Walk to Defeat ALS

6/11 - New Support Group - White Plains, NY in Westchester County.

6/15 - Bridgewater, NJ Walk to Defeat ALS

6/23 - Westchester Walk to Defeat ALS (Purchase, NY)

6/26 - Young Professionals Group monthly meeting (time & place TBD). For info contact Loren Domilici at ldomilici@als-ny.org or (212) 720-3060.

7/19 - ALS Awareness Day with Minor League Baseball's Brooklyn Cyclones - Join us in Coney Island for the Annual ALS Awareness Day. For details contact Kristen Cocoman at cocoman@als-ny.org or (212) 720-3048.

NEW BRUNSWICK / CENTRAL NJ

Special support group for newly diagnosed patients only and their families.

Saturday, June 29th - 1pm to 3pm

Robert Wood Johnson University Hospital, Medical Education Building
Room 108A, 180 Somerset Street, follow signs to meeting

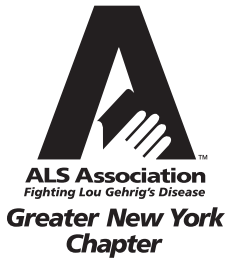
Contact: Debbie Schlossberg, LMSW and Mary Ann Mertz, RN (732) 710-8832

TELEPHONE SUPPORT GROUPS

For caregivers and patients. Summer schedule: will be held on a bi-weekly basis:

5/31, 6/14, 6/28, 7/26, 8/9, 8/23, 9/6, 9/20

Contact: Sue Zimmerman at (212) 720-3050



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Father's Day Tribute

I've been asked to write an article about my father. At first I thought, well this is will be nice, then immediately I thought wait, "How do I write this the correct way?" I do not want this to focus around ALS. Let me begin to tell you why.

This condition may in fact make it harder for people to walk, talk, breath, etc; but to me that does not make you weak. My father is one of the strongest people I know, even more so after being diagnosed with ALS. He has lost, I would say, eighty percent of his movement in his legs and is starting to lose the ability to do delicate tasks with his hands. Also like everyone else with this condition he gets upset from time to time and has to have a good cry. Again, none of this is a sign of weakness, because at no point does he stop.

Every day he gets up and continues to go to work to keep the doors of the business he started open and to continue to put food on the table for his two children

and his wife of twenty-eight years. He keeps his attitude positive not only for himself, but for his family and all his friends around him. He keeps their spirits high; we all know this condition takes a toll on all loved ones. He is willing to carry everyone's happiness on his shoulders. Even after pushing through an exhausting nine hour work day, he will go to two ALS Association support groups a month. If asked why? He responds with, "I want to go and make sure I keep everyone at those meetings upbeat."

Does that sound like the attitude of someone who was told "You have ALS?" If it does then you must be blessed to have someone as special as my father in your life. His goal is to continue being the man he was before his diagnosis and to help others who think it's not possible. I have seen even more strength come through my father during this long journey that he is going through, it maybe not always physically but emotionally for sure. I hope to one day be as strong as you Dad, I love you.

- Michael A. Najda, 25 -- Clifton, NJ

Summer Giving

Summer is fast approaching and we're looking forward to fun times in the sun and surf! Your donation during this cheerful time can help our Chapter provide area PALS with needed equipment to ensure they can experience summer fun as well - beach wheelchairs to enjoy a day on the sand and motorized wheelchairs for long excursions outside. Please support the Equipment Loan program to help improve lives by making a donation today to help us continue improving the quality of life for our PALS. For more information, please contact Loren Domilici at (212) 720-3060 or visit www.als-ny.org.

Team ALS: Running 4 A Cure in 2013

Team ALS is once again, an official charity partner of the ING New York City Marathon! With the cancellation of last year's Marathon, Team ALS members are more eager than ever to Run 4 A Cure in 2013! The Greater New York Chapter will have 10 official entries for this year's ING Marathon on November 3rd and also plans to welcome back several Team ALS alumni. For more information on how you can participate, please contact Kristen Cocoman at cocoman@als-ny.org or (212) 720-3048.