

The ALS Association Greater New York Chapter

October 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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October Support Groups

SUFFOLK COUNTY, NY

Tuesday, October 2nd - 6 pm to 8 pm
Stony Brook University, Dept. of Neurology
179 North Belle Meade Rd, E. Setauket
Speaker: Ben Lieman, Assistive Technologist,
ALS Association Greater NY Chapter
Topic: Assistive Technology for PALS
Contact: Theresa Imperato, RN, (516) 946-5467

HUDSON VALLEY, NY

Tuesday, October 2nd - 6:30 pm to 8:30 pm
Vassar Brothers Medical Mall
Ambulatory Surgery Center - Bldg C - 3rd Floor
200 Westage Business Center, Fishkill, NY
Topic: Relaxation Techniques
Speaker: Max Cohn, Massage Therapist
Contact: Helen Mayer, RN, (845) 520-0952

SADDLE BROOK / NORTHERN NJ

Thursday, October 4th - 7 pm to 8:30 pm
Kessler Institute for Rehabilitation
300 Market St., Saddle Brook, NJ
Topic & Speaker: Dave King, Physical Therapy & ALS
Contact: Debbie Schlossberg, LMSW (732) 710-8832

NASSAU COUNTY, NY

Sunday, October 7th - 2 pm to 4 pm
North Shore LIJ - Plainview Hospital
888 Old Country Road, Plainview - Downstairs
Speaker: Ben Lieman, Assistive Technologist,
ALS Association Greater NY Chapter
Topic: Assistive Technology for PALS
Contact: Theresa Imperato, RN, (516) 946-5467 and
Jody Wiesel, PhD (917) 699-9751

MANHATTAN, NY

Tuesday, October 16th - 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
Topic: Open Discussion
Contact: Jody Wiesel, PhD, (917) 699-9751

NEW BRUNSWICK / CENTRAL NJ

Saturday, October 20th - 1 pm to 3 pm
Robert Wood Johnson University Hospital
Medical Education Building, Rm. 108A
180 Somerset Street, follow signs to meeting
Topic: Open Discussion
Contact: Debbie Schlossberg, LMSW and
Mary Ann Mertz, RN, (732) 710-8832

TELEPHONE SUPPORT GROUPS

Caregivers: Fridays - 11 am to 12 pm
Patients: Fridays - 3 pm to 4 pm
Contact: Sue Zimmerman at (212) 720-3050

Healthy Breathing

by Mary Ann L. Mertz, RN, MA
Nurse Coordinator, ALS Association Certified Center of Excellence
Robert Wood Johnson University Hospital

Later this month we recognize National Respiratory Care Week. Ongoing respiratory health is a key factor and a vital component of care for anyone living with ALS.

Since the diaphragm and accessory breathing muscles can weaken in ALS patients, it may become difficult to move air in and out of the lungs. Some signs of breathing problems include shortness of breath, sleepiness during the day, poor quality sleep, frequent yawning, lower voice volume, fatigue, headaches or confusion. Unless there is another respiratory condition as well as ALS, supplemental oxygen is rarely needed. What is advantageous however, is early intervention for respiratory problems.

Here are some general, helpful hints:

- Seek the advice of your pulmonologist and/or ALS doctor regarding any perceived changes in breathing.
- Conserve energy. Rest between activities. Perform your most tiresome activities early in the day when you have the most energy.
- Use pillows or a wedge to elevate your head, shoulders and chest when sleeping.
- Getting the pneumonia vaccine and annual flu vaccines are usually advised. Try to "steer clear" of others who have a cold or influenza.
- Don't lie down immediately after a large meal as this can add pressure on the diaphragm. Smaller, more frequent meals are often best.
- Don't smoke!
- Review all of your medications with your physician, as some medications can impact breathing.

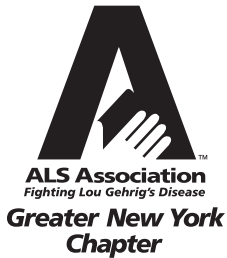
There are a number of non-invasive devices and techniques that may be helpful treatments as respiratory symptoms progress. Your doctor and respiratory therapist can suggest what is right for you, and can help you discern the pros and cons of choices for ventilatory (breathing) assistance.

October 21-27, 2012 is National Respiratory Care Week, yet attentive respiratory care everyday is key in the quest to breathe easy!

Walk to Defeat ALS - Fall Edition

On September 29th, we had a tremendously successful Long Island Walk to Defeat ALS. Thanks to all the Team Captains, Walkers, Volunteers, Special Guests and especially our top Corporate Team – Cullen's Crusades and top Family Team – For the Love of Jemmal!

Our last Walk of the year is coming up on Sunday, October 21st. The Hudson Valley Walk to Defeat ALS will span across the Walkway Over the Hudson from Highland to Poughkeepsie, NY and back. This scenic Fall event is a beautiful way to end the 2012 Walk season.



Greater New York Chapter
42 Broadway, Suite 1724
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f: 212-619-7409
www.als-ny.org

Empower our PALS

Through the generosity of numerous donors, our Chapter is able to provide our PALS with a wide array of equipment to help them maintain their independence, sustain mobility, and have the ability to communicate throughout the progression of the disease. Your gift, no matter the amount, can go a long way in helping us continue this important work for our region's PALS. Here is some of what your gift can provide:

- \$50 – **Switches** can give patients who have lost their ability to press on various communication devices access to an entire communication screen with one easy motion.
- \$150 – **Communication Device Batteries** allows our patients to be mobile and still maintain their communication. Communication systems can work while plugged in, but they become portable with the use of these batteries, fostering independence for patients and greater ease for caregivers.
- \$250 – **A Voice Amplifier** increases the volume of a patient with weakened or softened speech, so listeners can remain in a typical conversation space instead of staying extremely close to hear the speaker.
- \$350 – **Wheelchair Batteries** last about two years and provide one of the key components for a device that is critical to the movement of PALS. A power wheelchair cannot be used without a working battery, so this basic part of the wheelchair is one that is greatly needed for the Chapter.

Donate today to ensure we can continue to provide the highest quality of care to all our PALS and continue to provide the state-of-the-art equipment at no cost!

To donate or for more information,
contact Loren Domilici, Development Manager at
(212) 720-3060 or ldomilici@als-ny.org.



Later this month, the ALS Association Greater New York Chapter will team up with Art for ALS to raise funds and awareness for ALS. This unique art exhibit and silent auction will showcase a collection of works from 25 rising stars on the contemporary art scene. Photographs, prints, paintings and sculpture will be sold below market value in a silent auction at Site/109 gallery in the thriving art community of Manhattan's Lower East Side. The show also includes works by those directly impacted ALS.

It will be an inspiring evening of art, food, drink, and fun (light snacks, beer and wine will be served). Proceeds will benefit the ALS Association Greater New York to fund patient care and research for a cure. Together we can paint a brighter future.

When: October 24, 2012, 6pm to 10pm.

Bidding closes at 9:30pm sharp.

Where: Site/109, 109 Rivington St. NYC, (b/w Ludlow & Essex)

Suggested donation: \$30 at the door or online

More info: www.artforals.com or artforals2012@gmail.com.

Come. Be Inspired. Buy Art. Support ALS!

NATIONAL ALS REGISTRY - October marks the second anniversary since the National ALS Registry opened through the Centers for Disease Control & Prevention. As the third year unfolds, we should begin to see some of the preliminary results from the Registry.

If you are living with ALS and have not yet enrolled, please do so today. If you have enrolled, but have not completed the full array of surveys, it is important that you do so and provide as much information as possible. Please visit www.cdc.gov/als.

The more we know, the closer we get to a cure.

For more info about the registry go to www.als-ny.org or call Chris Dunn at the Chapter at (212) 720-3044.