



The ALS Association Greater New York Chapter

November 2013

Monthly Update

ALS Association
Fighting Lou Gehrig's Disease
Greater New York Chapter

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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November Support Groups - Celebrating National Caregivers Month!

All groups will honor our caregivers, thanks to all of you - each one of you is truly an inspiration!

NASSAU COUNTY, NY

Sunday, November 3rd - 2 pm to 4 pm
North Shore LIJ - Plainview Hospital
888 Old Country Rd., Plainview - Downstairs
Contact: Theresa Imperato, RN, (516) 946-5467
& Cindy Keyser-Posner, LMSW (631) 416-2767
Next month's support group meets December 1st.

SUFFOLK COUNTY, NY

Tuesday, November 5th - 6 to 8 pm
Stony Brook University, Dept. of Neurology
179 North Belle Meade Road
East Setauket, NY
Contact: Theresa Imperato, RN, (516) 946-5467
& Cindy Keyser-Posner, LMSW (631) 416-2767
Next month's support group meets December 3rd.

HUDSON VALLEY/FISH KILL, NY

Tuesday, November 5th - 6:30 to 8:30 pm
Ambulatory Surgery Center
Building C - 3rd Floor
200 Westage Business Center, Fishkill, NY
Contact: Helen Mayer, RN, (845) 520-0952
Guest speaker: Gioia Ciani, PhD,
Occupational Therapist
Next month's support group meets December 3rd.

WESTCHESTER, NY/WHITE PLAINS

Tuesday, November 12th - 6 to 8 pm
Burke Rehabilitation Center
785 Mamaroneck Avenue
Main Hospital, Building 7
1st Floor, Conference Room G-41
White Plains, NY
Contact: Helen Mayer, RN, (845) 520-0952
Guest speaker: Dale Lange, MD
Next month's support group meets December 10th.

NORTHERN NJ/SADDLE BROOK

Thursday, November 14th - 7 to 8:30 pm
Note: This is a date change for this month.
Kessler Institute for Rehabilitation
300 Market Street, Saddle Brook, NJ
Contact: Debbie Schlossberg, LMSW
and Mary Ann Mertz, RN, (732) 710-8832
Next month's support group meets December 5th.

CENTRAL NJ/NEW BRUNSWICK

Saturday, November 16th - 1 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
Next month's support group meets December 14th.

MANHATTAN, NY

Tuesday, November 19th - 6 to 8 pm
Phillips Ambulatory Care Center
(Beth Israel), 10 Union Square East
(b/w 14th & 15th streets)
Neurology Department
5th Floor Conference Room
Contact: Jody Wiesel, PhD, (917) 699-9751
Next month's support group meets December 17th.

TELEPHONE SUPPORT GROUPS

For caregivers and patients.

Caregivers group - every Friday from 11am to 12pm.

Patient group - every Friday from 3pm to 4pm.

Contact: Sue Zimmerman at (212) 720-3050

Upcoming Events

11/3 - ING New York City Marathon - GO Team ALS! To cheer on Team ALS at this year's NYC Marathon, meet us at the SW corner of 85th St. & 1st Ave. Please contact Kristen Cocoman at cocoman@als-ny.org or (212) 720-3048 for more info.

11/7 - The Nineteenth Annual Lou Gehrig Sports Awards Benefit. New York Marriot Marquis. Cocktails, silent auction, dinner and awards presentation. Honoring Mariano Rivera, Phil Simms, Ron Darling, & Kevin Turner. Emcee: Jeremy Schaap. Call (212) 619-1400 for more information and to purchase tickets.

11/12 - Young Professionals Group monthly meeting. Contact Loren Domilici at ldomilici@als-ny.org or (212) 720-3060 for info.

11/16 - Long Island Children and Teens Day. Dave and Busters, Farmingdale, NY. Ages 8-18 who have family members currently living with ALS. Arts & crafts, games, and socialization. Contact Theresa Imperato, RN at (516) 946-5467 or Cindy Keyser-Posner, LMSW at (631) 416-2767 for details - pre-registration is a must!

Give Thanks!

November is Caregivers Month - a time to be thankful for the caregivers in our lives and to remember those that continue to struggle with everyday finances while remaining the strong support in a family affected by ALS. We all know how important caregivers are in the lives of PALS; they are the dedicated force making the life of PALS a bit more comfortable.

Please take this time to show your thanks for the caregivers in your life by making a donation to help another. Your gift, will help the Chapter provide supportive services including counseling home visits to our Chapter's caregivers and will speak volumes to show our caregivers they are not in this alone. Together, we can take care of them.

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



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National Caregivers Month

by Adele Marano, LCSW, Director of Patient Services, Greater New York Chapter

When someone you love is diagnosed with ALS, the events that follow can result in a wide range of emotions -- from anxiety to feeling overwhelmed. For caregivers, these emotions, combined with the new demands placed on them can lead to a sense of frustration, loneliness, and guilt. In fact, more than 50 million people provide care for an ill, disabled or elderly family member or friend during any given year. A number of these caregivers take on their new responsibility as a full-time job.

Being a caregiver is hard work, involving emotional, financial, social, and nursing skills, often on a 24/7 basis. Many find themselves doing things they could not have previously imagined to ensure their loved one is properly cared for and their needs, both basic and complex, are met. However, when caring for another's needs, it's important to remember one's own needs, for a caregiver's work cannot get done if the caregiver is burned out.

Perseverance is a constant for ALS caregivers. But no matter how difficult the journey, please know that you are never alone. There are approximately 30,000 people living with ALS in the United States today and many times as many caregivers, some part-time, some full-time, some paid, some uncompensated, but regardless, all caregivers must be mindful to care for themselves, as well as the person with ALS in their life. Here are ten helpful tips that may help caregivers cope.

1. Choose to take charge of your life and don't let your loved one's illness or disability always take center stage.
 2. Remember to be good to yourself. Love, honor, and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
 3. Watch out for signs of depression, and don't delay getting professional help when you need it.
- *Feel free to speak to a Chapter social worker when they're visiting or calling your home. They are there as a resource, not just for the patient, but for caregivers as well. Also call the Chapter office to speak with a trained social worker.*

4. When people offer to help, accept the offer and suggest specific things that they can do. This brief respite could allow you to run errands, visit with friends and family, or just relax.

5. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.

- *The Chapter has an Assistive Technology Specialist - Ben Lieman - on staff to help you determine what equipment or augmentative communications device is right for you and the one you care for. Such equipment can help with a variety of daily tasks, from lifting to moving throughout the home, to communicating. Ben can be reached at blieman@als-ny.org or (212) 720-3057.*

6. Stand up for your rights as a caregiver.

- *The Chapter has a robust legion of ALS Advocates who work to seek change in government. The ALS Association also hosts National ALS Advocacy Day & Public Policy Conference each year. Become an ALS Advocate.*

For the full list of ten helpful tips for caregivers, please go to our website at www.als-ny.org.

To learn more about these or any of the services that the Chapter offers for caregivers, please call (212) 619-1400.

Saluting Our Veterans

On November 11th our nation commemorates Veterans Day, honoring those who have served in our country's armed forces. This is especially meaningful to the ALS community, as veterans are twice more likely to develop ALS than civilians.

To honor those veterans with ALS, The ALS Association created a Wall of Honor in tribute.

Go to www.als-ny.org and read about some of the outstanding veterans from our area.