



# Monthly Update

November 2015

**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  
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## NOVEMBER SUPPORT GROUPS

### NASSAU COUNTY, NY

Sunday, Nov. 1st - 2:00 to 4:00pm  
North Shore LIJ - Plainview Hospital  
888 Old Country Road  
Plainview, NY 11803 (Downstairs)  
Contacts: : Cindy Keyser-Posner, LMSW,  
(631) 416-2767  
Theresa Imperato, RN, (516) 946-5467  
Topic: National Caregivers Month/  
Open Discussion  
Next month's support group meets: Dec. 6th

### SUFFOLK COUNTY, NY

Tuesday, Nov. 3rd - 6:00 to 8:00 pm  
Stony Brook University, Dept. of Neurology  
179 N. Belle Meade Road  
East Setauket, NY 11733  
Contacts: : Cindy Keyser-Posner, LMSW,  
(631) 416-2767  
Theresa Imperato, RN, (516) 946-5467  
Topic: National Caregivers Month/  
Open Discussion  
Next month's support group meets: Dec. 1st

### HUDSON VALLEY/FISHKILL, NY

Tuesday, Nov. 3rd - 6:00 to 8:00 pm  
Ambulatory Surgery Center  
Building C, 1st Floor, Suite 130  
200 Westage Business Center  
Fishkill, NY 12524  
Contacts: Helen Mayer, RN,  
(845) 520-0952  
Nancy Brenner, LCSW, (914) 406-3513  
Topic: National Caregivers Month/  
Open Discussion  
Next month's support group meets: Dec. 1st

### WESTCHESTER, NY/WHITE PLAINS

Tuesday, Nov. 10th - 6:00 to 8:00 pm  
Burke Rehabilitation Center  
785 Mamaroneck Avenue  
Building 7  
White Plains, NY 10601  
Contacts: Helen Mayer, RN,  
(845) 520-0952  
Nancy Brenner, LCSW, (914) 406-3513  
Topic: National Caregivers Month/  
Open Discussion  
Next month's support group meets: Dec. 15th

### MANHATTAN, NY

Tuesday, Nov. 17th - 6:00 to 8:00 pm  
Mt. Sinai Beth Israel Hospital  
Phillips Ambulatory Care Center  
10 Union Square East  
(b/w 14th & 15th Sts.)  
New York, NY 10003  
Neurology Department  
5th Floor Conference Room  
Contact: Jody Wiesel, PhD, (917) 699-9751  
Topic: National Caregivers Month/  
Open Discussion  
Next month's support group meets: Dec. 15th

### NORTHERN NJ/SADDLE BROOK

Thursday, Nov. 5th - 7 to 9 pm  
Kessler Institute for Rehabilitation  
300 Market Street  
Saddle Brook, NJ 07663  
Contacts: Debbie Schlossberg, LMSW  
(732) 710-8832  
Mary Ann Mertz, RN, (908) 552-5573  
Topic: National Caregivers Month/  
Open Discussion  
Next month's support group meets: Dec. 3rd

### CENTRAL NJ/NEW BRUNSWICK

Saturday, Nov. 21st - 1:30 to 3:30 pm  
Robert Wood Johnson Fitness & Wellness Center  
100 Kirkpatrick Street  
New Brunswick, NJ 08901 Level 2  
Community Education Room  
Contacts: Debbie Schlossberg, LMSW,  
(732) 710-8832  
Mary Ann Mertz, RN,  
(908) 552-5573  
Topic: National Caregivers Month/  
Open Discussion  
Next month's support group meets: Dec. 19th

### TELEPHONE SUPPORT GROUPS

Patient group: Every Friday - 2:30 to 3:30 pm  
Caregivers group: Every Friday - 4 to 5 pm

Topics include: Open discussions or Meditation and Guided Imagery for Stress Reduction.  
Contact: Sue Zimmerman, LCSW, (212) 720-3050

## National ALS Registry Grows Into Powerful Research Tool

It's been seven years since the ALS Registry Act was signed into law establishing the first ever national patient registry for people living with ALS. The National ALS Registry web portal opened in 2010 and since that time, the registry has grown to become a powerful tool that not only collects vital information about the disease, including risk factors, but also is helping to advance ALS research.

- Seventeen risk factor modules are now available that enable people with ALS to provide information that may help researchers identify the causes of ALS.
- The registry program has funded ten external projects examining issues from the potential causes of ALS to caregiver responsibilities.
- The registry's research notification tool is expediting and facilitating enrollment in research studies and clinical trials. To date, more than 70,000 emails have been sent to people with ALS concerning nearly 20 different

ALS research studies and clinical trials for which they may qualify.

- The National ALS Biorepository has been created to collect blood and tissue samples and associate those samples with the risk factor and other information collected by the registry. People with ALS can contribute samples without having to travel to a center or clinic as health professionals collect samples through home visits.
  - More than 80 papers, abstracts, poster presentations and other publications related to the registry have been released, ranging from incidence and prevalence of the disease in specific states and metropolitan areas to the effects that demographic factors have on survival time.
- People living with ALS may self enroll in the Registry via a secure online web portal at the Centers for Disease Control and Prevention: [www.cdc.gov/als](http://www.cdc.gov/als).

**For assistance in enrolling in the National ALS Registry, contact Christine Dunn in the Chapter office at (212) 720-3044 or [dunn@als-ny.org](mailto:dunn@als-ny.org).**



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# HONORING CALS DURING NATIONAL CAREGIVERS MONTH

Caregivers of ALS patients (often called CALS) are the unsung heroes of the ALS community. Oftentimes the work of family members or friends who tend to the health and comfort of a person with ALS (PALS) is greatly underestimated. A 2015 study by the National Alliance for Caregiving (NAC) found that caregivers spend on average about 24 hours a week providing care to a loved one and almost a quarter provide 41 or more hours of care per week. The NAC also estimated the cost of services provided by family caregivers at \$375 billion a year, twice as much as real dollars spent on homecare and nursing home services combined (\$158 billion). At the Chapter, we know that caregivers are priceless and at times they need a little TLC of their own.

PALS Janet Palkewick is in her 29th year with PLS, a related condition to ALS. "She has an amazing family who has cared for her for all these years," said Debbie Schlossberg, LMSW, Patient Services Coordinator in New Jersey. "Janet lives with her daughter Elisabeth and her family. Not only does Elisabeth help out but Janet's sons and four grandchildren pitch in every day as well."

Elisabeth says the best coping advice she can give to CALS is to remember to take some time for yourself. "To be the best possible CALS to our PALS, we need to care for our own emotional and physical state," she said. "Cry if you need to, shout if you need to, eat an extra scoop of ice cream if you need to. Just take care of yourself because you are no good to your PALS if you are run down and worn out." As a caregiver, she said don't go it alone; reach out to others when you need something. "It takes a village. Don't be afraid to ask for help. People need specific directions and nine times out of ten they want to help but don't know how. Just ask."

Elisabeth also said that communication with doctors and insurance companies are key, especially knowing what paperwork needs to be filled out on behalf of your PALS. "This will clear up

any privacy laws and it is easier to get these papers taken care of while your PALS has a clear voice," she said.

Rose Coleman's daughter Debbie Ruggiero is a longtime patient at the chapter's ALSA Certified Treatment Center of Excellence at Rutgers Robert Wood Johnson Medical School. Rose said she will go above and beyond for her daughter but having a routine is one of the most important things to her as a CALS. "I could never go without a routine," she said. "Everybody finds their own way of doing things. I have my own." She also says that having a Home Health Aide come in for a few hours every day helps give her a little break.

According to Tracy Sandy-Ali, BA, CCRC, LPN, the chapter's Intake and Support Program Manager, caregiver-focused support groups and seminars draw some of the biggest attendance numbers when compared to other similar types of groups. "So there is the need for dedicated support forums for caregivers," she said.

Elisabeth said she finds the chapter's monthly support groups very helpful for both PALS and CALS. "It gives CALS the opportunity to share like experiences and help one another when we need a lift," she said. "Caring for your PALS is the most rewarding gift you could give them. This is also the most precious gift you can give yourself."

The ALS Association Greater New York Chapter's November support groups will highlight Caregiver needs. The chapter also offers weekly telephone support groups for caregivers every Friday from 4 to 5 pm. Contact: Sue Zimmerman, LCSW at (212) 720-3050 for more info.

**Go to [www.als-ny.org](http://www.als-ny.org) for further details on monthly support groups meeting places and times.**