

The ALS Association Greater New York Chapter

November 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](http://www.als-ny.org)  
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## November Support Groups

*November is National Caregivers Month!  
All groups will be honoring our wonderful  
caregivers. Thanks to all of you who give so much.  
Each one of you is an inspiration!*

### SADDLE BROOK / NORTHERN NJ

Thursday, November 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

### NASSAU COUNTY, NY

Sunday, November 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  
Jody Wiesel, PhD (917) 699-9751

### SUFFOLK COUNTY, NY

Tuesday, November 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

### HUDSON VALLEY, NY

Tuesday, November 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

### NEW BRUNSWICK / CENTRAL NJ

Saturday, November 17th - 1 pm to 3 pm  
Robert Wood Johnson University Hospital  
Medical Education Building, Rm. 108A  
180 Somerset Street, follow signs to meeting  
Contact: Debbie Schlossberg, LMSW and  
Mary Ann Mertz, RN, (732) 710-8832

### MANHATTAN, NY

Tuesday, November 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

### TELEPHONE SUPPORT GROUPS

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

## Veterans Day Tribute

The month of November marks a special time in the life of our nation's veterans. As we commemorate Veterans Day we reflect on our military heroes who fought valiantly for this country and sacrificed so much in the name of freedom. We in the ALS community are especially mindful of our veterans, as those who serve in the military are twice as likely to develop ALS, regardless of branch of service or combat duty status.

For those veterans living with ALS, there is a wonderful opportunity to talk about your military service and about ALS in your own words. The national office of The ALS Association maintains on their website the Wall of Honor to salute our military heroes living with ALS. We encourage all veterans to visit the site -- <http://www.alsa.org/advocacy/veterans/> and tell your story.

To all veterans, we salute you.

## On Your Mark, Get Set... GO TEAM ALS!!!

Sunday, November 4th marks the 43rd annual ING New York City Marathon. The marathon is the ultimate pinnacle of personal perseverance, determination, endurance, and will. As in previous years, the 2012 marathon will include runners with extra spirit and heart, as they run to raise funds and awareness for ALS. Known as Team ALS: Running 4 A Cure, over a dozen runners seek to raise a combined total of \$100,000 to benefit patient services and to fund cutting-edge research to find a cure.

Among those participating is Dorothy Halsey. Dorothy ran the marathon last year in honor of her family friend Mark Kravitz. This year, she runs in his memory, as he died on September 30th. He was her Dad's college roommate and her brother's godfather, as well as a U.S. District Court Judge and was 62-years-old. Dorothy has trained all summer and has raised over \$12,000. Her goal for this year is \$15,000.

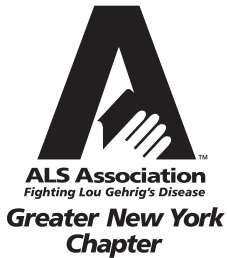
And for the third year in a row, Craig Williams is running in the marathon in memory of his brother Paul, who lost his battle with ALS in June 2010, just 13 months following his diagnosis at the age of 44. Originally from Australia, Craig now lives in Mountainside, New Jersey.

To meet other Team ALS members and hear their stories, check out the Chapter's Facebook page in the week leading up to the marathon.

## Caring for Caregivers

November is National 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, however small, will speak volumes to show our caregivers they are not in this alone. To donate contact Loren Domilici at (212) 720-3060.



Greater New York Chapter  
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## NOVEMBER IS NATIONAL CAREGIVERS MONTH

This month we honor all caregivers, who are on the front lines of the fight against ALS and see the ravages of the disease every single day. The men and women who care for their mother, father, spouse, grandparent, neighbor, friend, or child do so with determination, compassion, and a will from which they must summon enough strength for themselves and for their loved ones. Here is one such story, of a family on Long Island.

Maria Guercia, 47, resides in New Hyde Park on Long Island with her husband Roland, who is living with ALS and will turn 50 later this month. They have two children - a daughter Alexa, 17, who is a senior in high school and plays on the varsity field hockey and lacrosse teams, and a son Jake, 12, who is in the 7th grade and plays quarterback for the football team. Maria and Roland have been together 26 years and married for 22 of those years.

In our interview with Maria, she was able to offer some key advice about being a caregiver. First, say everything upfront.

Don't hold back on the love and the hurt and all that you feel. Put it all out there so you can move on with the care and move on with your lives. Roland has accepted ALS, but has not accepted dying. He is living and will continue to do so until he can no longer. Maria also urges those newly diagnosed and their families to "make the call." Talking to the ALS Association Greater New York Chapter "made a world of difference to us."

Life began to change one day when Roland, an extremely good cook according to Maria, was making his famous chili. As someone who was ambidextrous, Roland could maneuver a number of pots and pans with ease, but that day in early 2009 he began to have trouble turning some pots with his left hand. After months of falling, difficulties using the computer, and experiencing problems with his speech, Roland was diagnosed with ALS in September of 2010. Just a year later, confined to either a wheelchair or to bed, Roland developed pneumonia and was hospitalized for nearly three months. He thankfully beat that bout and returned home.

To read the entirety of the article go to [www.als-ny.org](http://www.als-ny.org).

**THANKSGIVING BOUNTY!** *by Ilene Kapelner, Registered Dietician, ALSA Center at Beth Israel Medical Center.* It's once again time to plan the Thanksgiving meal. For PALS, it is important to ensure that a meal is not only nutritional and tasty, but also easy to swallow. Here are some easy to chew, traditional dishes modified to add extra moisture and calories for the whole family to enjoy.

One simple way to do so is to add gravy, an essential to any Thanksgiving meal. Also, don't forget to balance your menu with plenty of autumn fruits and vegetables such as: squash, spinach, and cranberries - all high in vitamins A, B, and C, potassium, antioxidants, and fiber.

Here is one starter to the meal that is seasonal, easy to swallow, and delicious. For other takes on traditional Thanksgiving recipes, such as Sweet Potato/Marshmallow Casserole, Apple Crisp Cheesecake, and Pumpkin Pie Smoothies, visit [www.als-ny.org](http://www.als-ny.org). **Happy Thanksgiving!**

### PUMPKIN SOUP

- 3/4 cup water
- 1 small onion, chopped
- 1 can (8 ounces) pumpkin puree
- 1 cup unsalted vegetable broth
- 1/2 teaspoon ground cinnamon
- 1/4 teaspoon ground nutmeg
- 1 cup half and half
- 1/8 teaspoon freshly ground black pepper
- 1 green onion, green top only, chopped

In a large saucepan, heat 1/4 cup of the water over medium heat. Add the onion and cook until tender, about 3 minutes. Don't let the onion dry out.

Add the remaining water, pumpkin, broth, cinnamon and nutmeg. Bring to a boil, reduce heat and simmer for 5 minutes. Stir in the milk and cook until hot. Don't boil.

Ladle into warmed individual bowls and garnish with black pepper and green onion tops. Serve immediately.