



**Greater New York Chapter**

1994 · 20th Anniversary · 2014

The ALS Association Greater New York Chapter

July 2014

# 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

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## Save the Dates – 2014 Walks to Defeat ALS

Long Island, NY: Saturday, Sept. 20 • Hudson Valley, NY: Sunday, Oct. 19

### JULY SUPPORT GROUPS

#### NASSAU COUNTY, NY

*Due to July 4th Holiday, there is no Meeting in July.*

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: August 3rd.*

#### SUFFOLK COUNTY, NY

Tuesday, July 1st - 6 to 8 pm  
Stony Brook University  
Department of Neurology  
179 N. Belle Meade Rd., E. Setauket, NY  
Contact: Theresa Imperato, RN, (516) 946-5467  
& Cindy Keyser-Posner, LMSW (631) 416-2767  
Topic: The importance of fluids in the summer.  
*Next month's support group meets: August 5th.*

#### HUDSON VALLEY/FISHKILL, NY

Tuesday, July 1st - 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: Ben Lieman, ATP,  
Greater NY Chapter  
*Next month's support group meets: August 5th.*

#### NORTHERN NJ/SADDLE BROOK

Thursday, July 3rd - 7 to 8:30 pm  
Kessler Institute for Rehabilitation  
300 Market Street, Saddle Brook, NJ  
Contact: Debbie Schlossberg, LMSW  
and Mary Ann Mertz, RN, (732) 710-8832  
Guest speaker: Anna Baratta, RD, MS  
Topic: Nutrition & ALS  
*Next month's support group meets: August 7th.*

#### WESTCHESTER, NY/WHITE PLAINS

Tuesday, July 8th - 6 to 8 pm  
Burke Rehabilitation Center  
785 Mamaroneck Avenue, Bldg. 7  
(Patient Dining Room), White Plains, NY  
Contact: Helen Mayer, RN, (845) 520-0952  
Guest speaker: Jennifer Mertz,  
Physical Therapist from Burke Rehab  
*Next month's support group meets: August 12th.*

#### MANHATTAN, NY

Tuesday, July 15th - 6 to 8 pm  
Phillips Ambulatory Care Center  
(Mt. Sinai Beth Israel)  
10 Union Square East (b/w 14th & 15th Sts.)  
Neurology Dept., 5th Floor Conf. Room  
Contact: Jody Wiesel, PhD, (917) 699-9751  
Topic: Bring your concerns for open discussion.  
*Next month's support group meets: August 19th.*

#### CENTRAL NJ/NEW BRUNSWICK

**Please note new time and location:**  
Saturday, July 19th - 1:30 to 3:30  
Robert Wood Johnson  
Fitness & Wellness Center  
Level 2, Community Education Room  
100 Kirkpatrick St., New Brunswick, NJ  
Park in the Fitness & Wellness parking deck.  
(3-hour free parking; bring the parking deck ticket in with you.)  
Contact: Debbie Schlossberg, LMSW and  
Mary Ann Mertz, RN (732) 710-8832  
Topic: A discussion of Medical Marijuana,  
followed by open discussion  
*Next month's support group meets: August 16th.*

#### TELEPHONE SUPPORT GROUPS

**Patient group:** Every other Friday from 3 to 4 pm (Throughout the summer.)  
**Caregivers group:** Currently on a brief hiatus.  
If you are interested in joining this particular group, please contact Sue Zimmerman, LCSW at (212) 720-3050 or Zimmerman@als-ny.org.  
For general telephone support group information, call Sue as well.

### Upcoming Events

**Thursday, July 17th** - ALS Awareness Night with The Staten Island Yankees. Free tickets available. For more info, contact Kristen Cocoman at Cocoman@als-ny.org or (212) 720-3048

**Tuesday, July 22nd** - The Long Island Walk to Defeat ALS Kick-Off Party and Awards Presentation. For more info or to RSVP, contact Sarah Pattison at spattison@als-ny.org or (212) 720-3042.

**Thursday, July 24th** - ALS Awareness Night with The Brooklyn Cyclones. Free tickets available. For more info, contact Kristen Cocoman at Cocoman@als-ny.org or (212)720-3048.

**Saturday, July 26th** - The Hudson Valley Walk to Defeat ALS Kick-Off Party and Awards Presentation. For more info or to RSVP, contact Sarah Pattison at spattison@als-ny.org or (212)720-3042.

### National ALS Registry

The Federal government has taken a major step in the fight against Lou Gehrig's Disease as the Agency for Toxic Substances and Disease Registry (ATSDR) announced the full implementation of the National ALS Registry.

People living with Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease) 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 more information about the registry go to: [www.als-ny.org](http://www.als-ny.org) or contact Christine Dunn in the Chapter office at (212) 720-3044 or [dunn@als-ny.org](mailto:dunn@als-ny.org). She can also assist you in with your enrollment.



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## Patients and Families Tell Us Their ALS Stories

During May, ALS Awareness Month, we asked you to tell us your story. The response was overwhelming. People wrote to us to tell us of their loved ones who fought this disease and PALS took the time to let us know their personal stories and how they live with ALS every day.

We published them all on our website in hopes that the stories help the public put names and faces to the letters "A-L-S" and understand the urgent need for more awareness and support.

Please read through a summary of some of the stories below. To read them all, head to our website at [www.als-ny.org](http://www.als-ny.org). The more people who know about ALS, the better chance we have of funding research to find a cure and further our mission of providing critical care and support to patients and their families.

### **There is No Norm When it Comes to Norm** *by Melanie Holzberg*

In fact, Norm Holzberg upstaged the rabbi at his own funeral. Norm wrote his own eulogy, holding the audience captive for over an hour, as he knew he could. A splendid storyteller and master schmoozer, the loss of speech was probably the hardest for him to deal with than any of the other symptoms. And how many of us can write our own farewells to those we love? Norm did that, making us laugh and cry at the same time. His final words were not to mourn his death, but rather to celebrate his life. The funeral director told us that in 45 years he had never seen a funeral like it, with so much laughter. That was so much like Norm.

Norm was determined to fight ALS with everything he had. And he did, usually bravely, sometimes not. He chose to go on the respirator and get a feeding tube so that he could live to watch Scott and Shara, our children grow up. But Norm still did not understand how disabled he was. If you got him up and dressed and put him in the van, he was off anywhere you could drag him.

He did more with his life than most healthy people I know did. He continued to be a warm and caring husband, father, and friend to all.

### **PALS William Loveless' Story**

My name is Bill Loveless, I was diagnosed two years ago with ALS. The direction the disease has taken with my body is the gradual deterioration of the "bulbar muscle," which controls breathing, swallowing, voice, and tongue movement. My neck muscles have weakened to the point that I can't hold my head up and the left side of my body is weaker than my right. With all of this, I still say I am blessed. I can see, hear, taste, and I'm still capable of walking short distances. Most of all I have a loving wife and daughter – and friends that are there to help me!

Before I was diagnosed, I was an active guy at work and at home. I enjoyed the outdoors, doing carpentry work around our home and for others. I always thought I was a strong person. I am six foot seven inches tall and two years ago I weighed 250 pounds. Today I weigh 200 pounds. I guess I never really knew the meaning of strength. Now I do.

### **PALS Luis Caso's Story**

During 2008, I was diagnosed with juvenile Amyotrophic Lateral Sclerosis (ALS). I had been experiencing difficulty with walking and maintaining my balance. After extensive medical examinations and tests, Parkinson's disease and Charcot Marie Tooth (CMT) were ruled out. Apparently, I've been suffering with this disease all of my life but over the past few years it has taken a turn for the worse. Although at present time I use a cane in order to ambulate, my prognosis is that sometime within the next few years I will most likely end up in a wheelchair. Considering all of the other potential outcomes, it is a blessing that my condition has been somewhat stable (on occasion my ability to swallow and digest food is compromised). For me it is a very curious disease, and I am thankful to God that I am still able to meaningfully function (considering how the disease attacks others in a more insidious manner). I pray that all those who are suffering with this condition will one day be free from the pain of this most serious of experiences.

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**Do you have a story to share? Send your story to Kim Peters at [kpeters@als-ny.org](mailto:kpeters@als-ny.org) or visit our website [als-ny.org](http://als-ny.org).**