



ALS Association
Fighting Lou Gehrig's Disease

**Greater New York
Chapter**

The ALS Association Greater New York Chapter

February 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

February Support Groups

****NEW** SADDLE BROOK / NORTHERN NJ**

Thursday, February 2nd - 7 pm to 8:30 pm
Kessler Institute for Rehabilitation
300 Market St., Saddle Brook, NJ
Topic: Open Discussion Inaugural Meeting
Contact: Debbie Schlossberg, LMSW (732) 710-8832

NASSAU COUNTY, NY

Sunday, February 5th - 2 pm to 4 pm
North Shore LIJ - Plainview Hospital
888 Old Country Road, Plainview - Downstairs
Topic: Super Bowl Party
Contact: Theresa Imperato, RN, (516) 946-5467 and
Jody Wiesel, PhD (917) 699-9751

SUFFOLK COUNTY, NY

Tuesday, February 7th - 6 pm to 8 pm
Stony Brook University, Dept. of Neurology
179 North Belle Meade Rd, E. Setauket
Topic: Understanding emotional lability
Contact: Theresa Imperato, RN, (516) 946-5467

HUDSON VALLEY, NY

Tuesday, February 7th - 6:30 pm to 8:30 pm
Ambulatory Surgery Center - Bldg C - 3rd floor
200 Westage Business Center, Fishkill, NY
Contact: Helen Mayer, RN, (845) 520-0952
Speaker: Jeffrey Abrant, elder care attorney

NEW BRUNSWICK / CENTRAL NJ

Saturday, February 18th - 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
Topic: Respiratory Care; Speaker: Dr. Philip Schiffman

MANHATTAN, NY

Tuesday, February 21st - 6 pm to 8 pm
Phillips Ambulatory Care Center (Beth Israel)
10 Union Square East (b/w 14th & 15th streets)
2nd Floor- Conference Room #1
Contact: Jody Wiesel, PhD, (917) 699-9751
Speaker: Gioia Ciani - Occupational Therapist

TELEPHONE SUPPORT GROUPS

Caregivers: Wednesdays - 11 am - 12 pm
Patients: Wednesdays - 3 pm - 4 pm
Adult children of PALS: Friday - 11 am - 12 pm
Contact: Sue Zimmerman at (212) 720-3050

Countdown to the 2012 Walk to Defeat ALS Season REGISTRATION OPENS FEBRUARY 1st!

Yes, that's right, the **2012 Walk to Defeat ALS** season is here and the registration site will open for business on February 1st! The ALS Association Greater New York Chapter Walk Staff is just back from Nashville, Tennessee where the National Walk to Defeat ALS Conference was held and they are ready to rock & roll!!

This year the first Walk will commence on Saturday, May 5th in New York City. Other Walk dates that have been confirmed are: Long Branch, NJ Walk (Sunday, May 20th), Long Island Walk (Saturday, September 29th), and the Hudson Valley Walk (Sunday, October 21st). The Westchester, NY & Saddle Brook, NJ Walks will be confirmed shortly! Log on to our Walk website at www.alswalks.org for information or to register for a Walk in your area starting Feb. 1st.

Stay tuned for more Walk updates and the latest news on Kick-Off events. Follow the Walk to Defeat ALS in our region on Facebook (www.facebook.com/ALSWalks) and on Twitter (@WalktoDefeatALS) for up-to-the-minute information, innovative fundraising tips, and to track your team's progress.

Lace up those sneakers and let's get walkin'!

Help Find a Cure

Become a member of The ALS Association Greater New York Chapter Research Council.

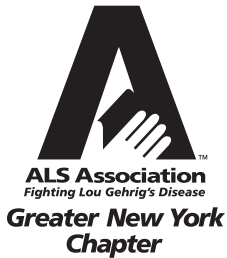
The Research Council is an annual giving program that acknowledges the important support of individuals who make gifts of \$1,000 or more annually to research.

Members of the Greater New York Chapter Research Council play an important role in funding aggressive, cutting-edge ALS research. This year you can help find a cure for ALS.

For more information, please contact Janet Diminich, Senior Development Officer at (212) 720-3060 or jdiminich@als-ny.org.

Log In & Tune In

Find out the latest on ALS research, advocacy, patient service technology, events and more! Follow us on Facebook (www.facebook.com/ALSofGNY) and on Twitter (@ALSofGNY). Like us, follow us, and get important information on all everything related to ALS and the Chapter.



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

A 'Celebration of Life': Kathy's Story

by Rob Borkes



I'd like to share the story of my sister, Kathleen Borkes. Kathy was always everyone's angel; she led an extraordinary life of always caring for others before herself. Our mother, Dorothy, was diagnosed with ALS, back in the mid-90s and fell victim to it in 1997. Our father, George, and our grandmother would soon pass as well.

She took care of them all for over ten years.

Kathy thought she finally had the chance to get her own life back. However, in the spring of 2010, after months of the 'bulbar' symptoms having surfaced she was also diagnosed with ALS. Ironically, she would now need the handicapped-ready house she bought for our parents for her own challenges - never complaining, just trying to do what she had to do to accept her condition as her strength diminished.

Shortly after her diagnosis Kathy wrote a thank you note to me, saying: "I struggled with why you had been given this tremendous burden of my illness and care. Why this? Why now? Not for us to ask. We just have to do our best and live life to the fullest!"

Kathy willed herself to stay with us for the college graduation of our nephew, Chris. As she miraculously got closer to her 50th birthday on October 4, 2011, I asked her one more time if she would be up to a family gathering.

Amazingly she said yes, even after having said to me: "Do you really think it would be a good idea? I know I am failing and everyone will be making another trip very shortly, for my funeral. I wouldn't want people to come out twice."

The great part to this story is that she agreed to it anyway. She wanted to share her love for her family and friends that she had throughout her amazing life. Kathy was very specific that I was to design a card that didn't speak of her 50th birthday, but I was to call it her "Celebration of Life."

On October 8, 2011 the weather was perfect and the house quickly filled with those who meant so much to her. Even in her weakened state, she was able to visit with them all. The morning after, she sent an email to us that read: "I never felt so very loved! I left my room yesterday morning into a magical, beautiful wonderland of a home! Amazed, surprised, a warm fuzzy feeling!! Never thought I could feel that again... what an absolutely lovely day!"

A week later, we invited those who couldn't make it and other close support group friends from New Jersey. My amazing sister would pass away less than two weeks later. At peace, finally.

I am so grateful for the gift I received, the lessons I learned from Kathy through her acceptance, patience, and just the dignified way she lived her life. What I am trying to say is to celebrate the joy you have brought to others, even through these difficult times. You might be surprised just how much your family and friends want to tell you how much you mean to them and that they love you. "Celebrate your Extraordinary Lives!"