



Monthly Update

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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1994 · 20th Anniversary · 2014

Save the Dates – 2014 Walks to Defeat ALS

- NYC: Saturday, May 3 • Long Branch, NJ: Sunday, May 18 • Saddle Brook, NJ: Sunday, June 8 • Westchester, NY: Saturday, June 14
- Somerset, NJ: Saturday, June 21 • Long Island, NY: Saturday, Sept. 20 • Hudson Valley, NY: Sunday, Oct. 19

MAY SUPPORT GROUPS - MAY IS ALS AWARENESS MONTH

NORTHERN NJ/SADDLE BROOK

Thursday, May 1st – 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
 Topic: Open Discussion
Next month's support group meets: June 5th.

NASSAU COUNTY, NY

Sunday, May 4th – 2 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
 Topic: May is ALS Awareness Month
Next month's support group meets: June 1st.

SUFFOLK COUNTY, NY

Tuesday, May 6th - 6 to 8 pm
 Stony Brook University, Dept. 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: May is ALS Awareness Month
Next month's support group meets: June 3rd.

HUDSON VALLEY/FISHKILL, NY

Tuesday, May 6th - 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
 Topic: Open Discussion
Next month's support group meets: June 3rd.

WESTCHESTER, NY/WHITE PLAINS

Tuesday, May 13th - 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
 Topic: Open Discussion
Next month's support group meets: June 10th.

CENTRAL NJ/NEW BRUNSWICK

Saturday, May 17th - 1 to 3pm
 Rutgers Robert Wood Johnson Medical School
 Medical Education Building
 Room 108A, 180 Somerset Street
 Contact: Debbie Schlossberg, LMSW and
 Mary Ann Mertz, RN (732) 710-8832
 Topic: Open Discussion
Next month's support group: To be announced.

MANHATTAN, NY

Tuesday, May 20th - 6 to 8 pm
 Phillips Ambulatory Care Center (Beth Israel)
 10 Union Square East (b/w 14th & 15th Sts.)
 Neurology Dept., 5th Floor Conf. Room
 Contact: Jody Wiesel, PhD, (917) 699-9751
 Guest speaker: Eileen Kapeler, Nutritionist
 Topic: The importance of nutrition
 and the ALS patient
Next month's support group meets: June 17th.

TELEPHONE SUPPORT GROUPS

Patient group - Every other Friday from 3 to 4 pm starting May 9th (through the summer.)

Caregivers group - Currently on a brief hiatus.

For more information please contact Sue Zimmerman, LCSW at (212) 720-3050

Upcoming Events

5/3 – New York City Walk to Defeat ALS. To register or donation, visit our website at: www.alswalks.org.

5/7 - 5/9 – National ALS Advocacy Day & Public Policy Conference in Washington, DC. For more information, please contact Kim Peters at (212) 720-3054 or kpeters@als-ny.org.

5/18 – Long Branch Walk to Defeat ALS. To register or donation, visit our website at: www.alswalks.org.

Are you planning an event in your community to raise funds and awareness for ALS in 2014? Whether it's a bake sale, a rummage sale, a poker night, or a happy hour, you can organize an event in your community that suits you. For more ideas on how you can help raise funds and awareness for research and patient services contact Ally Davis at adavis@als-ny.org.

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

For more information about the registry go to: www.als-ny.org or call the Chapter office at (212) 619-1400.

If you need help enrolling in the registry, please contact Christine Dunn at (212) 720-3044 or dunn@als-ny.org.



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MAY IS ALS AWARENESS MONTH. YOU CAN GET INVOLVED!

Seventy five years after Lou Gehrig gave his famous retirement speech in Yankee Stadium on July 4, 1939, there is still no cure or effective treatment for ALS, the disease that took the life of the legendary "Iron Horse" and now bears his name. To bring attention to this disease that continues to devastatingly impact our lives, every May we commemorate ALS Awareness Month with events, media and a number of other awareness raising activities.

There is no better tool for awareness than your ALS story. Take some time out of your day and give voice to that story. Most people know who Lou Gehrig was, but they should also know about the life of your dad, your mom, your sister, your brother, your aunt, uncle or cousin, your neighbor, your colleague, and you.

One of the best ways to make your ALS story known is to write your community newspaper. Call them or go online and see how to submit a Letter to the Editor or an Op-Ed piece. Throughout the Greater New York region, there are a number of online community news outlets.

Look for the neighborhood or town nearest you. Write to the editor and tell them about ALS and how it has impacted you and your family. Educate people who are not as familiar with ALS to learn about it through your story. For assistance or questions, please contact Regina Ackley at (212) 720-3047 or ackley@als-ny.org.

Here are some more ways you can get involved with the Greater New York Chapter during ALS Awareness Month:

We kick off the month with the first Walk to Defeat ALS of 2014 on Saturday, May 3rd in New York City when thousands of people come together at Hudson River Park to make the two mile walk. If you're interested in participating, sign up at www.alswalks.org or contact Sarah Pattison at (212) 720-3042 or spattison@als-ny.org.

We continue our awareness campaign with the National ALS Association Advocacy Day and Public Policy Conference in Washington D.C. from Wednesday, May 7th through Friday, May 9th, when our Greater New York Chapter Delegation heads to Capitol Hill with PALS and other advocates to tell our ALS stories to our elected officials and push for more funding for ALS research. If you're interested in joining us, contact Kim Peters at (212) 720-3054 or kpeters@als-ny.org.

Our next Walk to Defeat ALS will be held at the beautiful seaside promenade in Long Branch, NJ on May 18th. Sign up at www.alswalks.org or contact Sarah Pattison at (212) 720-3042 or spattison@als-ny.org for more information.

The Chapter's website (www.als-ny.org) has information about these and other ALS Awareness Month activities, as well as news about research and services. You can always call the Chapter at (212) 619-1400. We are here to help!

ALS Awareness All Year Round *May isn't just about flowers and ALS Awareness month!*

Extend your support in May and beyond by helping to improve the quality of life for people with ALS not only today but every day. To make a donation or for more information, please visit www.als-ny.org or contact Kim Peters at (212) 720.3054 or kpeters@als-ny.org.