



The ALS Association Greater New York Chapter

September 2014

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

www.ALS-NY.org • Facebook.com/ALSoFGNY • Twitter - @ALSoFGNY

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Save the Dates – 2014 Walks to Defeat ALS

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

SEPTEMBER SUPPORT GROUPS

SUFFOLK COUNTY, NY

Tuesday, September 2nd - 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: Open discussion
Next month's support group meets: October 7th

HUDSON VALLEY/FISHKILL, NY

Tuesday, September 2nd - 6:30 to 8:30 pm
Ambulatory Surgery Ctr, Bldg C, 3rd Floor
200 Westage Business Center, Fishkill, NY
Contact: Helen Mayer, RN, (845) 520-0952
Topic: Walk to Defeat ALS
Guest speaker: Sarah Pattison,
Greater New York Chapter
Next month's support group meets: October 7th

NORTHERN NJ/SADDLE BROOK

Thursday, September 4th - 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: Handicapped Accessible Vehicles
Guest speaker: Silio Garcia, Fun Truck'n
Next month's support group meets: October 2nd

NASSAU COUNTY, NY

Sunday, September 7th - 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: Open discussion
Next month's support group meets: October 5th

WESTCHESTER, NY/WHITE PLAINS

Tuesday, September 9th - 6 to 8 pm
Burke Rehabilitation Center
785 Mamaroneck Avenue
Building 7 (Patient Dining Room)
White Plains, NY
Contact: Helen Mayer, RN
(845) 520-0952
Topic: Medicaid & Special needs planning
Guest speaker: Sarah Meyers, ESQ
Next month's support group meets: October 14th

CENTRAL NJ/NEW BRUNSWICK

No meeting in September due to Long Island Walk to Defeat ALS.
Robert Wood Johnson Fitness & Wellness Ctr.
Level 2, Community Education Room
100 Kirkpatrick St., New Brunswick, NJ
Park in the Fitness & Wellness parking deck.
Contact: Debbie Schlossberg, LMSW and
Mary Ann Mertz, RN (732) 710-8832
Next month's support group: October 18th.

MANHATTAN, NY

Tuesday, September 16th - 6 to 8 pm
Phillips Ambulatory Care Ctr. (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: Disability & Homecare options for ALS
patients & their families
Speaker: Sue Zimmerman, LCSW,
Greater New York Chapter
Next month's support group meets: October 21st

TELEPHONE SUPPORT GROUPS

Patient group: Every other Friday from 3 to 4 pm (Throughout the summer. Weekly groups will resume in the late fall.)

Caregivers group: Currently on hiatus. Will resume in fall. If you are interested in joining this 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

Wednesday, Sept. 3rd - YPG Happy Hour Fundraiser from 6 - 9 pm at Public House, 140 E. 41st St., NYC. \$10 tickets for Happy Hour prices all night! Contact Alexandra Davis at (212) 720-3049 or adavis@als-ny.org for more info.



Saturday, Sept. 20th
Long Island, NY
Eisenhower Park

Sunday, Oct. 19
Hudson Valley, NY
Walkway over the Hudson

To Register Visit www.ALSWALKS.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 or contact Christine Dunn in the Chapter office at (212) 720-3044 or dunn@als-ny.org. Chris can help you with your enrollment.

The CDC will be publishing the first data set from the National ALS Registry in the agency's Morbidity and Mortality Weekly Report (MMWR) on July 25th. For more information about the ALS Registry, contact Tracy SandyAli at (212) 720-3060 or tsandyali@als-ny.org.



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Update: The ALS Ice Bucket Challenge



By now you've no doubt heard about the ALS Ice Bucket Challenge that has taken the nation by storm. People are literally soaking themselves to raise awareness and funds for ALS while figuratively "pouring cold water on the disease" in hopes of finding a cure. While a fun activity that is perfectly tailored for the YouTube-era, the viral videos haven't only taken over social media but have contributed to an avalanche of awareness and funding for The ALS Association's many chapters.

On Monday, August 25th, The ALS Association's national office and its 38 chapters have received a combined \$79.7 million in donations compared to \$2.5 million during the same time period last year (July 29 to August 25). These donations have come from existing donors and over 1.7 million new donors to The Association. The Greater New York Chapter itself has seen a tremendous increase in donations during this same time period receiving \$3.4 million versus \$102,000 in 2013. The Chapter also had 63 new teams sign up for our two fall Walks to Defeat ALS.

We are thrilled at the level of awareness and dollars the challenge is generating. Coming during what for most charities is typically a very slow time of year in terms of fundraising, we're especially thankful to the thousands of people who've been doused with ice water and/or donated to fight this devastating disease.

In case you don't know how it works: To make a challenge, post a video of yourself pouring a bucket of ice water over your head to your social media page. In the video, explain why you are doing it - to raise awareness and money to support the fight against ALS. Then challenge three others to do the same within the next 24 hours or they have to make a donation to The ALS Association -- and preferably both!

The inspiration for the ice bucket challenge for ALS began with two Westchester families, the Senerchias and the Quinns, and went viral with the Frates family in Boston. Since then, celebrities, politicians and sports stars have taken part in the challenge on television and social media and the news media has been covering the phenomenon as it sweeps the nation.

While the amount of money raised is truly remarkable, we also value the visibility that ALS is receiving, as before this effort, only about half of the general public was aware of the disease.

Never before have we been in a better position to fuel our fight against this disease. With increased awareness and unprecedented financial support comes incredible opportunity. We are strategizing now about the most effective ways to invest this generous outpouring of support that will make the biggest difference in the fight against ALS and look forward to considering innovative projects that have been unfunded to date, as we continue to deliver on our existing mission-critical priorities in the areas of research, care services and public policy.

We look forward to keeping you apprised of our activities in the coming months and to updating you on research breakthroughs, as our common goal as members of the ALS community is to find a treatment and a cure for Lou Gehrig's disease.

Thank you for your generous support!

To learn more about the ALS Ice Bucket Challenge and see many of the great videos go to our website at www.als.org.