



# 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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## 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

## APRIL SUPPORT GROUPS

### SUFFOLK COUNTY, NY

Tuesday, April 1st - 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  
 Speaker: Melissa Negrin-Wiener, Esq.  
 Topic: Future Planning & Community Medicaid  
*Next month's support group meets: May 6th.*

### HUDSON VALLEY/FISHKILL, NY

Tuesday, April 1st - 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: Open Discussion  
*Next month's support group meets: May 6th.*

### NORTHERN NJ/SADDLE BROOK

Thursday, April 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 Speakers: Sarah Pattison and Loren Domilici, The Greater New York Chapter  
 Topics: Walk to Defeat ALS and National ALS Advocacy Conference  
*Next month's support group meets: May 1st.*

### NASSAU COUNTY, NY

Sunday, April 6th – 2 to 4 pm  
 North Shore LIJ - Plainview Hospital  
 888 Old Country Road  
 Plainview - Downstairs  
 Contact: Theresa Imperato, RN,  
 (516) 946-5467 and  
 Cindy Keyser-Posner, LMSW  
 (631) 416-2767  
 Speaker: Richard Weinblatt, Esq.  
 Topic: Future Planning & Community Medicaid  
*Next month's support group meets: May 4th.*

### WESTCHESTER, NY/WHITE PLAINS

Tuesday, April 8th - 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  
 Guest Speaker: Kim Peters,  
 The Greater New York Chapter  
 Topic: National ALS Advocacy Conference  
*Next month's support group meets: May 13th.*

### CENTRAL NJ/NEW BRUNSWICK

*(Please note change in date for this month)*  
 Saturday, April 12th - 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  
 Guest Speaker: Sarah Pattison,  
 The Greater New York Chapter  
 Topic: Walk to Defeat ALS and  
 National ALS Advocacy Conference  
*Next month's support group meets: May 17th.*

### MANHATTAN, NY

*(Please note change in date for this month)*  
 Tuesday, April 22nd - 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: Sarah Pattison,  
 The Greater New York Chapter  
 Topic: Walk to Defeat ALS  
*Next month's support group meets: May 20th.*

## TELEPHONE SUPPORT GROUPS

Patient group - Every Friday from 3 to 4 pm. | Caregivers group - Every Friday from 4 to 5 pm.  
 Contact: Sue Zimmerman, LCSW at (212) 720-3050

## Upcoming Events

4/4 – Join NYC Walk Team “Stormin 4 Norman” & Hospital For Special Surgery at a Dinner Party Fundraiser 4 ALS on Friday, April 4th at Il Tesoro in NYC. For info call Sarah Pattison at (212) 720-3042.

4/5 – New York City Canvassing Day! Please join us from 11AM -1PM us as we spread the word around New York City about the Walk to Defeat ALS. hanging posters and displaying brochures in your neighborhood. Coffee and Bagels will be provided! For more details, please contact Rebecca Silver Fisher at (212) 720-3043.

4/6 – Children and Teens Bereavement Group. For more information, contact Sue Zimmerman at (212) 619-1400.

4/16 – Young Professionals Group Happy Hour at Public House. For more details, please call Rebecca Silver Fisher at (212) 720-3043.

## Team ALS Joins the 2014 TCS New York City Marathon as a Bronze Partner!

Applications now being accepted to run with Team ALS in the 2014 TCS New York City Marathon!

**TEAM ALS  
 RUNNING 4 A  
 CURE**

For information on securing a spot the Marathon and other races throughout the year, contact:

Kristen Cocoman, Director of Marketing & Special Events at cocoman@als-ny.org or (212)720-3048.

**Reserve Your Spot Now!**



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## PALS MAKE A DIFFERENCE IN WASHINGTON DC AT THE NATIONAL ALS ADVOCACY DAY AND PUBLIC POLICY CONFERENCE

This coming May, ALS Association Advocates from all over the country will meet up in Washington, DC to visit with members of Congress. This powerful annual event in our nation's capitol has brought about big wins for the ALS Association in support of patients, including:

- Generating more than \$800 million in government funding for ALS research since 1998.
- Establishing regulations so that people with ALS automatically meet the medical eligibility requirements for Social Security Disability Insurance.
- Eliminating the 24-month Medicare waiting period for ALS.
- Working with the VA to make ALS a service connected disease, providing veterans with ALS and their survivors access to the highest level of health and disability benefits.
- Enacting the National ALS Registry to establish the single largest ALS research program ever created.

While much has been accomplished, there is still much to do and we are asking every person and family member affected by ALS to join the Greater New York Chapter delegation from May 7-9 this year for the National ALS Advocacy Day and Public Policy Conference.

Janet Palkewick, from N. Haledon, NJ, a mother of four who has lived with Lou Gehrig's Disease for more than 20 years, says one of the most important reasons to go to Washington DC is to put a face on the disease.

"With these PALS all coming to the meetings, our Senators, Congressmen and their aides can personally see the 'human side' of ALS and what it does to families," said Janet.

When she was diagnosed in 1989, Janet was busy raising three kids and had a fourth baby on the way. She says life became "a real challenge for all of us" and after her diagnosis she never expected to see her baby go to kindergarten.

"Not only have I been blessed to see him grow up but also I've lived to see each of my other three children graduate college, marry, buy their own homes and have children," said Janet who now has six grandchildren.

For the past six years Janet has gone to Washington, DC for the Advocacy Conference, becoming an integral part of The ALS Association's delegation on Capitol Hill. She says she will continue to go "as long as I am able, to speak for my fellow PALS who are not able to and for the ones who have already lost their ALS battle."

Janet travels from her home in New Jersey to Washington, DC with her daughter every year and she has often also been accompanied by her sons and grandchildren. "My 7-year-old grandson went last year and my 10-year-old granddaughter is going for her second time this year," Janet said. "As you can see ALS Advocacy is important to my family!"

Lawmakers get to see firsthand how the disease affects more than just the patient. "During the meetings, all the members of our group – PALS and family members – share their unique ALS stories and how it has affected their lives," described Janet. "At the end of each meeting, the leader of the group presents a request for support of the legislative and funding priorities that have been established by the ALS community."

Out of everything Advocates have accomplished in Washington DC, Janet is most proud of the National ALS Registry. Janet was one of the first participants invited to do a test run of the website before it launched.

For those who are deciding whether to attend Advocacy Day this year, Janet says, "Go if you can because the accomplishments are so rewarding. You will be in a group with other people who have been at Advocacy Day previously, and you will never be physically, mentally, or emotionally alone. You will never regret what you are doing for yourself, PALS and all those whose lives have been touched by ALS. We are all connected."

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**Join The ALS Association Greater New York Chapter from Wednesday, May 7th through Friday, May 9th for the National ALS Advocacy Day and Public Policy Conference in Washington, DC.**

**For information contact Development Manager Loren Domilici at (212) 720-3060 or [ldomilici@als-ny.org](mailto:ldomilici@als-ny.org).**