



The ALS Association Greater New York Chapter July 2009

# Monthly Update

**ALS Association**  
Fighting Lou Gehrig's Disease

Serving Greater New York and Northern and Central New Jersey  
42 Broadway, Suite 1724, New York, NY 10004, 800-672-8857 f: 212-619-7409 www.als-ny.org

## July Support Groups

### NASSAU COUNTY, NY

NO GROUP IN JULY

(1st Sunday of every month)

North Shore's Central General Hospital

888 Old Country Road, Plainview

Downstairs Meeting Room; (516) 719-3000

Facilitators: Theresa Imperato, RN - (631) 444-4623

Jody Wiesel, PhD - (917) 699-9751

### SUFFOLK COUNTY, NY

July 7, 2009 6:00-8:00 PM

(1st Tuesday of every month)

Stony Brook University, Dept. of Neurology

179 Belle Meade Rd, E. Setauket

(631) 444-1970

**Topic: Walk to Defeat ALS**

**Speaker: Allison Lardner, Walk manager**

Facilitator: Theresa Imperato, RN - (631) 444-4623

### NEW BRUNSWICK, NJ

July 18, 2009 1:00-3:00 PM

(3rd Saturday of every month)

Robert Wood Johnson University Hospital

Medical Education Building, Rm 108A

180 Somerset Street, Follow signs to meeting.

**Topic: Nutrition**

**Speaker: Anna Baratta**

Facilitators: Debbie Schlossberg, LMSW

(732) 710-8832

Mary Ann Mertz, RN

### MANHATTAN, NY

July 21, 2009 6:00-8:00 PM

(3rd Tuesday of every month)

Phillips Ambulatory Care Center (Beth Israel)

10 Union Square East (Bet. 14th & 15th St.)

2nd Floor, Conference Room #1

**Topic: Open Discussion**

Facilitator: Jody Wiesel, PhD - (917) 699-9751

*For more information about our Support Groups:  
Go to the Patient Services section at  
www.als-ny.org or call 800-672-8857.*

## Long Island Walk to Defeat ALS Kick-Off Cocktail Party Thursday, July 16, 2009, 6:30pm Westbury Manor, Westbury, NY

Please join us in kicking off the 2009 Long Island Walk Season!

During this fun filled evening receive your 2008 Walk award, pick up your Walk promotional materials, and learn about new fundraising tips to make the 2009 season your team's most successful!!

For more information, contact

Allison or Kristina at (212) 619-1400 or walk@als-ny.org



## **SAVE THE DATE!** **Long Island Walk to Defeat ALS** **Saturday, Sept. 12**

**Allison Lardner, Walk Manager,**  
alardner@als-ny.org, (212) 720-3042

**Kristina Wertheimer, Marketing Coordinator,**  
Desantis@als-ny.org, (212) 720-3049



**The NY Chapter has a Lending Library available to all PALS.**  
We have DVDs of movies & TV shows and books on CD or audio tape to lend.  
Please contact Christine Dunn at the Chapter office or e/mail dunn@als-ny.org.





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**VOLUNTEER NIGHT July 23, 2009 5-7 PM. Contact Christine @ 212-720-3044**

## CALENDAR of EVENTS

**7/4/09** - Fourth Of July 4ALS Yankees Game. Tickets available for purchase. Call Jennifer Lowy at (212) 619-1400 for pricing and details.

**7/16/09** - 2009 Long Island Walk Kick-Off Cocktail Party. 6:30PM. Westbury Manor. Contact: Allison Lardner, Alardner@als-ny.org, (800) 672-8857.

## PLEASE GIVE!

*Leave A Legacy of Hope*



### CHARITABLE GIFT ANNUITY

A gift annuity is a simple contract between you and **The ALS Association Greater New York Chapter**. In exchange for your gift of cash or stock, The ALS Association Greater New York Chapter makes regular payments to you, you and your spouse or someone you name, for life. The remaining principal goes to The ALS Association Greater New York Chapter when the contract ends.

For information please call  
 Beth Mohsinger at (212) 720-3060  
 or email: mohsinger@als-ny.org

## 2009 National ALS Advocacy Day and Public Policy Conference: Advocacy Delivers the Roadmap to a Cure

*The power of the conference is found in the people attending and the knowledge that families impacted by ALS are not alone in the fight – that they can make a difference.*

Advocates from across the country representing the entire ALS community came together for the 2009 conference to share their hopes and experiences and to join The ALS Association in creating the roadmap that will lead to a treatment and cure.

Unlike virtually anything else experienced by families with ALS, advocacy presents people with the opportunity to play an active role in the fight against the disease - to fight back against ALS.

Armed with a story to tell and a passion to make a difference, hundreds of ALS Advocates who attended this year's conference flooded the Halls of Congress and met with nearly 400 Senators and Representatives. The goals:

- To continue funding for the national ALS Registry, which may become the single largest ALS research project ever created; and
- To double funding for the ALS Research Program (ALSRP) at the Department of

Defense (DOD), a program whose sole mission is to develop a treatment for ALS.

It is clear that the meetings made an impact as 33 Senators signed a letter calling on the Senate to increase funding for the ALSRP to \$10 million - the largest number to ever sign onto our DOD funding letter. The support generated this year – in just a matter of days – was greater than similar letters supporting other disease research. Why? Because advocates told the ALS story, put a face on the disease, and



made a policy issue personal. After all, Members of Congress can't forget shaking the hand of a person with ALS who no longer can return the grip. As one attendee said, "I believe the personal visits make it impossible

for our message to get lost in the shuffle."

Join Us in 2010! The ALS Association encourages the entire ALS community to join us for next year's conference, which takes place May 9-11, 2010. And please participate in The Association's year-round advocacy efforts by signing-up to become an ALS Advocate TODAY! Call the chapter for details.