



The ALS Association Greater New York Chapter

# 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, 212-619-1400 f: 212-619-7409 www.als-ny.org

## April Support Groups

### SUFFOLK COUNTY, NY

April 6, 2010 6:00-8:00 PM  
(1st Tuesday of every month)  
Stony Brook University, Dept. of Neurology  
179 North Belle Meade Rd, E. Setauket  
(631) 444-1970

**Topic: Open Discussion.**

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

### NASSAU COUNTY, NY

**PLEASE NOTE: This is a schedule change.**

April 11, 2010 2:30-4:00 PM  
North Shore's Central General Hospital  
888 Old Country Road, Plainview  
Downstairs Meeting Room; (516) 719-3000

**Topic: Open Discussion.**

Facilitators: Theresa Imperato, RN - (631) 444-4623  
Jody Wiesel, PhD - (917) 699-9751

### NEW BRUNSWICK, NJ

April 17, 2010 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: Walks and Special Events.**

**Speaker: Allison Lardner**

Facilitators: Debbie Schlossberg, LMSW  
(732) 710-8832  
Mary Ann Mertz, RN

### MANHATTAN, NY

April 20, 2010 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: Legalese & ALS**

**Speaker: Jeffrey Abrandt**

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](http://www.als-ny.org) or call 212-619-1400.

## 2010 Walk to Defeat ALS

Join us for a day of fun, food and music  
- and finding a cure for ALS!

**Woodbridge Walk- Sunday, May 2**

**New York City Walk - Saturday, May 15**

**Long Branch Walk - Sunday, May 23**

**Saddle Brook Walk - Sunday, June 6**

**Westchester Walk - Sunday, June 13**

**Long Island Walk - Sunday, Sept. 26**

For more information go to: [www.alswalks.org](http://www.alswalks.org).

We look forward to achieving greatness together this season.  
Please contact us with any questions you may have!

**Allison Lardner, Walk Manager,**  
[alardner@als-ny.org](mailto:alardner@als-ny.org), 212.720.3042

## The ALS Association's National ALS Advocacy Day & Public Policy Conference.

**WASHINGTON, DC - MAY 9-11, 2010**

To attend the 2010 national ALS Advocacy Day & Public Policy Conference, please register online at [www.alsa.org/policy/alsday.cfm](http://www.alsa.org/policy/alsday.cfm) or call the Advocacy Department at (212) 619-1400. To receive reduced registration rates, please register no later than April 9, 2010.

### CALLING ALL VOLUNTEERS

Volunteers are critical to The ALS Association Greater New York Chapter's success. We've always relied on volunteer support to keep our office running efficiently and to pitch in for all of our special events.

If you are looking for a way to get involved we would love to meet with you for an interview and to discuss your interests. If you are interested in a New York assignment please contact Ms. Kayvan Freeman at [freeman@als-ny.org](mailto:freeman@als-ny.org) or call 212-720-3055 to schedule an appointment. For New Jersey assignments please contact Ms. Debbie Schlossberg at [schlossberg@als-ny.org](mailto:schlossberg@als-ny.org) or call 732-710-8832.



**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](mailto:dunn@als-ny.org).





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## NATIONAL ALS REGISTRY UPDATE



**Pilot Project Results, Identifying Cases Pilot Projects** - Over a nearly three year period, the CDC sponsored four pilot projects in order to create the building blocks for the registry. The projects evaluated several different strategies to

identify ALS cases, learning how to overcome the significant challenges of effectively and efficiently ascertaining cases of ALS, a disease that progresses rapidly, is not easily diagnosed and often is misdiagnosed or confused with other diseases. The projects also examined challenges associated with obtaining data. Preliminary results from the projects were presented to the CDC in June 2009 and are guiding the next steps in creating the registry.

**National Databases (Medicare, Medicaid, VA)** - Using data learned from the projects, the CDC has created an algorithm that will enable the Agency to accurately identify approximately 80 - 85% of ALS cases in the United States by examining large national administrative databases, such as those maintained by Medicare, Medicaid and the Veterans Administration. Once an ALS case is identified via this method, it will be included in the National ALS Registry.

**How to Identify ALS Cases: Web Portal, Self Registration** - In order to identify the remaining 15-20% of cases, the CDC is launching an on line web portal that will allow people with ALS to self enroll in the registry via a secure website. The first phase of the portal ([www.cdc.gov/als](http://www.cdc.gov/als)) was unveiled in October 2009 and currently includes general information about ALS and answers to frequently asked questions. **Self registration is expected to begin in late 2010.**

**Next Steps** - The ALS Association is working closely with the CDC to take the steps that are necessary to fully implement the registry as soon as possible. Several vital activities will be taking place in the coming months and we are pleased to share with you a timeline that outlines what will be happening.

**Enrolling in the Registry** - Although self enrollment in the ALS registry has not yet begun, The ALS Association is working with the CDC to ensure that as many people with ALS as possible enroll in the registry once self enrollment is

available. Therefore, we urge all PALS to sign up as ALS Advocates.

By selecting ALS Registry when signing up, PALS will be notified as soon as the self enrollment phase of the web portal becomes operational and they also will receive detailed instructions on how they can enroll.

*We will provide additional information about the ALS registry as it becomes available. If you have any questions, please contact us at [als@als-ny.org](mailto:als@als-ny.org) or tollfree at 1 877 444 ALSA.*

*For a more comprehensive update please go to our website at [www.als-ny.org](http://www.als-ny.org) and click the link "Update on the ALS Registry."*

### **VOLUNTEER IN-HOME VISIT PROGRAM**

The New York Chapter is pleased to announce the expansion of our long-standing volunteer program to now include home visit assistance and companionship.

Would you like help with tasks or errands, yard work or correspondence? Would you like companionship to listen to music or enjoy a book? Maybe you would like someone to walk your dog or help prepare a special meal. Volunteers can provide all this and much much more!

If your family can use help with any tasks, whether they be one-time projects or on-going in nature, we may be able to help. Contact Kayvan Freeman in New York at 212-720-3055 or [freeman@als-ny.org](mailto:freeman@als-ny.org) or Debbie Schlossberg in New Jersey at 732-710-8832 or [schlossberg@als-ny.org](mailto:schlossberg@als-ny.org).

In order to guarantee optimum quality, volunteers are interviewed and operate under the supervision of chapter professional staff.