



# 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-nj.org

## November Support Groups

### NASSAU COUNTY, NY

November 1, 2009 2:00-4:00 PM  
(1st Sunday of every month)  
North Shore's Central General Hospital  
888 Old Country Road, Plainview  
Downstairs Meeting Room; (516) 719-3000  
**Topic: Caregiver's Month**  
Facilitators: Theresa Imperato, RN - (631) 444-4623  
Jody Wiesel, PhD - (917) 699-9751

### SUFFOLK COUNTY, NY

November 3, 2009 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: Caregiver's Month**  
Facilitator: Theresa Imperato, RN - (631) 444-4623

### MANHATTAN, NY

November 17, 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: Support For The Caregiver**  
**Speaker: Carol Bishop, RN**  
Facilitator: Jody Wiesel, PhD - (917) 699-9751

### NEW BRUNSWICK, NJ

November 21, 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: Caregiver's Month**  
Facilitators: Debbie Schlossberg, LMSW  
(732) 710-8832  
Mary Ann Mertz, RN

*For more information about our Support Groups  
go to the Patient Services section at:  
www.als-nj.org or call 212-619-1400.*

## 2009 Walks To Defeat ALS: It's Still Not Too Late To Donate!

We're nearing our goal for the year and we can still use your help. Did you know that you can still donate to any of the Walk to Defeat ALS teams until 2010? Go to our website at [www.als-nj.org](http://www.als-nj.org) and click on our Walk to Defeat ALS banner to donate. Contact us at 212-619-1400 or email [walk@als-nj.org](mailto:walk@als-nj.org) if you have any questions.

As you know, the need for patient services programs for those stricken with ALS is ever present and we continue to help fund important ALS research. Together we will reach our goal. Together we will help families with ALS. Thank you for helping make this year's Walks to Defeat ALS so successful.

## CALENDAR of EVENTS

**November 2009, National Family Caregiver Month Educational Series.** In honor of National Family Caregivers' Month in November 2009, a set of presentations has been designed specifically for caregivers providing attention and care to people living with ALS. Please join us for informative and practical discussions, sharing of experiences, tips and support. Caregivers, family, people living with ALS and friends are invited to attend these web-based presentations. For more information please go to [www.als-nj.org](http://www.als-nj.org) or call 212-619-1400.

**11/4/09, ALS Association's Young Professionals Group Cocktail Party Fundraiser.** Tribeca Grand Hotel, 2 Avenue of the Americas (Bet. Walker and White Streets), NY, NY 10013 An evening of Cocktails, Food, Music & Auction. Open bar & sponsored beer & vodka combo. Tickets: \$75 in advance/\$80 at the door. Contact: Allison Lardner, [Alardner@als-nj.org](mailto:Alardner@als-nj.org) or 212-619-1400.

**11/12/09, 15th Annual Lou Gehrig Sports Awards Benefit.** Marriott Marquis, New York, NY Honoring Richard "Goose" Gossage, Curtis Martin, Dominique Wilkins and Bernie Williams. The Jacob K. Javits Lifetime Achievement Award will be presented to George Vecsey. Presenter will be Bob Costas and the Master of Ceremonies is Jeremy Schaap.

**11/15/09, Notre Dame Club of the Mid-Hudson Valley ALS Walk.** The Notre Dame Club of the Mid-Hudson valley presents an ALS Walk in Memory of Gus Raspitha PhD '70. For more information please contact Allison Lardner at [Alardner@als-nj.org](mailto:Alardner@als-nj.org) or call 212-619-1400..

**11/19/09 VOLUNTEER NIGHT! 5-7 PM. Call Christine at 212-720-3044**



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





**Greater New York Chapter**  
**42 Broadway, Suite 1724**  
**New York, NY 10004**  
212-619-1400  
f: 212-619-7409  
www.als-ny.org

First-Class Mail  
U.S. Postage  
PAID  
New York, N.Y.  
Permit No. 7566

## **Focus On: Caregiving: Will You Sink Or Swim As A Caregiver?**

By Debbie Schlossberg, LMSW

“When people confront an ocean of need, they feel anxiety. Some run for their lives; others jump in and drown. Both reactions are rooted in the inability to stay separate and set limits in a healthy way that balances generosity with self-preservation.” - Roberta Satow, Chair, Dept. of Sociology, Brooklyn College.

“Balancing generosity and self-preservation” is an interesting lens from which to view a caregiver’s dilemma. One end of the spectrum is the inclination to give all of oneself in an attempt to take away our loved one’s distress, to prove the extent of our love. At the other, the inability to face this formidable foe—to turn away and not offer ourselves as much as we should. Both are extremes in equally futile attempts to erase the reality of ALS. Most caregivers are able to swim somewhere in the middle but there is always the pull of the tide, the guilt for not “jumping in” more. Occasionally the undertow of responsibility is too great for us to bear and it compels us to run away more than is healthy or safe.

So how do you find and keep this steady stroke? How do you keep your head above water without tiring out?

Some caregivers have difficulty describing their coping skills. They view



them as a natural aspect of who they are and how they operate. Others can enumerate specific tools. What I’ve observed is that there are certain traits caregivers possess that enable them to attain and maintain this balance:

1) Caregivers who maintain balance are caregivers who set limits. They’re

able to take stock of who they are: their strengths and capabilities as well as areas where they have perhaps always tended to seek assistance. With this self-knowledge they construct boundaries. They work to do the best they can within these contours and get help for the rest. By doing this, they minimize the potential anger, resentment, and emotional and physical depletion that can come from striving to meet a bar set too high.

2) They are often good communicators. When faced with a task too great, they know how to say, “I really wish I could do this. But I can’t.”

3) More than anything else, they work hard with the “Re’s”. Re-defining. Re-visiting. Re-inventing. Because they realize that what was normal, what used to work,

changes every day when living with ALS. This is perhaps the hardest piece. The importance of maintaining a fluidity, a flexibility. Like the waves which ebb and flow, our seascape changes daily and the best swimmer knows not to fight the current, but to try and let it carry you.