

Monthly Update



Greater New York Chapter
116 John St., Suite 1304
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www.als-ny.org

NOVEMBER SUPPORT GROUPS

NASSAU COUNTY, NY

November 5, 2006 2:00-5:00 PM

North Shore's Central General Hospital

Old Country Road, Plainview

Downstairs Meeting Room

Switchboard: (516) 719-3000

Topic: Caregiver Month

Facilitators: Theresa Imperato, RN
Jody Wiesel, PhD

SUFFOLK COUNTY, NY

November 7, 2006 6:00-8:00 PM

(1st Tuesday of every month)

Stony Brook University Hospital

Nichols Road, Stony Brook

Heart Center Conference Room,

Main Floor

Switchboard: (631) 689-8333

Topic: Caregiver Month

Facilitators: Theresa Imperato, RN
Sheralda Brown-Small,
LCSW

NEW BRUNSWICK, NJ

November 18, 2006 1:00-3:00 PM

(3rd Saturday of every month)

Robert Wood Johnson University Hospital

Medical Education Building, Room 108A

Follow signs to meeting place

Topic: Caregiver Month

Facilitators: Debbie Schlossberg LMSW
Mary Ann Mertz, RN

MANHATTAN, NY

November 21, 2006 6:00-8:00 PM

(3rd Tuesday of every month)

Phillips Ambulatory Care Center (BIMC)

10 Union Square East

Between 14th and 15th Street

2nd Floor, Conference Room #3

Topic: Caregiver Month

Facilitator: Eileen Mullarkey, LCSW

SUPPORT GROUP CONTACT INFO

Theresa Imperato, RN:

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Eileen Mullarkey, LCSW:

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Debbie Schlossberg, LMSW

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NOVEMBER IS CAREGIVERS MONTH

When someone you love is diagnosed with ALS, the events that follow can result in a wide range of emotion - from anxiety to feeling overwhelmed. For caregivers, these emotions, combined with the new demands placed on them can lead to a sense of being alone. In fact, more than 50 million people provide care for an ill, disabled or elderly family member or friend during any given year*. A number of these caregivers take on their new responsibility as a full-time job. Seventeen percent of caregivers provide 40 hours of care a week or more**. Being a caregiver is hard work, involving emotional, financial, social and nursing skills twenty-four hours a day, seven days a week.

For Caregivers Month, *Family Caregiving 101* offers ten tips for caregiver.***:

1. Choose to take charge of your life and don't let your loved one's illness or disability always take center stage.
2. Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
3. Watch out for signs of depression, and don't delay getting professional help when you need it.
4. When people offer to help, accept the offer and suggest specific things that they can do.
5. Educate yourself about your loved one's condition. Information is empowering.
6. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
7. Trust your instincts. Most of the time they'll lead you in the right direction.
8. Grieve for your losses and then allow yourself to dream new dreams.
9. Stand up for your rights as a caregiver and a citizen.
10. Seek support from other caregivers. There is great strength in knowing you are not alone.

For more information about caregiving resources, visit the National Family Caregivers Association at www.nfca.org, or the National Alliance of Caregiving at www.caregiving.org. *Family Caregiving 101* at www.familycaregiving.org is a combined effort of the NFCA and the National Alliance of Caregiving that answers common caregiving questions, provides outreach and resources for caregivers.

For more information about services and resources offered by the Greater New York Chapter, please call 800.672.8857.

*Source: U.S. Department of Health and Human Services, *Informal Caregiving: Compassion in Action*. Washington, DC: 1998, and National Family Caregivers Association, *Random Sample Survey of Family Caregivers, Summer 2000*, Unpublished.

**Source: National Alliance for Caregiving and AARP, *caregiving in the U.S., 2004*.

*** Source: *Family Caregiving 101, Ten Tips for Family Caregivers*, www.familycaregiving101.org.

DONATE THROUGH YOUR IRA

The Pension Protection Act of 2006 allows donors to make charitable gifts directly from an IRA without generating taxable income. Eligible donors, 69 and a half or older, may transfer up to \$100,000 per year for the 2006 and 2007 tax years. The gifts may be made in addition to any other charitable giving a donor has planned. These charitable distributions count toward minimum required distribution requirements.

If you live in New Jersey, a state that does not provide income tax breaks for charitable gifts, this is an incentive to utilize The IRA Charitable Rollover to direct charitable funds. Please discuss The IRA Charitable Rollover with your financial advisor.

For more information on directing these funds to The ALS Association Greater New York Chapter, contact Beth Mohsinger at 800-672-8857 or mohsinger@als-ny.org.



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VOLUNTEER NIGHT November 16th 5-7 PM Contact Chris @ 212.720.3044

Opportunities  and Announcements

On November 1st, The ALS Association will be teaming up with Chores-For-Charity. Founded by teenager, Ilana Rothbein, Chores-For-Charity will give teens the opportunity to designate a percentage of their earnings from a part-time job, summer job, babysitting or odd-jobs to go to The ALS Association. The employer signs the Chores-For-Charity log specifying the hours worked and the hours of pay being donated to The ALS Association. **Contact Jason Scott at 800.672.8857 for more information, or visit www.als-ny.org.**

Catch Celebrity Jeopardy at 7:00 p.m. on ABC on Thursday, November 9th to see Boston Red Sox pitcher, Curt Schilling go against *Desperate Housewives'* Doug Savant and Jane Kaczmarek from *Help Me, Help You*. PALS, Fern Cohen, Norma Hess and Stan Silver, along with other members of the Greater New York Chapter's ALS community cheered Curt on as he competed for \$50,000 to go to The ALS Association.

Pick up Michelle Wildgen's *You're Not You*, which tells the story about the relationship between young and inexperienced caregiver, Bec, and 36-year-old Kate, a PALS in the final stages of the disease. **Read Phyllis Robinson's review of *You're Not You* at www.als-ny.org.**

Calendar of  Events

October 29 - "Ask the Experts" ALS Symposium at the Cold Spring Harbor Laboratory, Grace Auditorium in Cold Spring Harbor, Long Island from 1:00 p.m. to 4:00 p.m. For more information or to RSVP, call Chris Dunn at 800.672.8857.

November 1 - 12th Annual Lou Gehrig Sports Awards Benefit, honoring Yogi Berra, Mike Eruzione and Oksana Baiul at the Marriott Marquis, NYC. For more information, visit www.lougegrigsportsawards-benefit.org or call Jenn Lowy at 800.672.8857.

November 4 - An Evening in Las Vegas at North Shore Synagogue. \$75 per person includes open bar, buffet dinner, \$100 voucher towards chips and a raffle dinner. For more information, contact 516.921.2282

November 8 - ~~Theater Night, Jersey Boys.~~ For tickets, call Shelley Finkelstein at 212.709.9154. **SOLD OUT**

November 9 - Bette Jean Benefit Showcase for ALS Awareness and Research at the Galapagos Art Space in Williamsburg, Brooklyn. \$10 at the door. For more information email alsbenefit.bettejean@gmail.com.

November 16 - New Jersey "Ask the Experts" ALS Symposium at Rutgers University Busch Campus Center in Piscataway, New Jersey from 6:00 p.m. to 9:00 p.m. For more information, call Chris Dunn at 800.672.8857.

November 18 - Musicians Fight ALS 6 at The Hook in Brooklyn. **Visit www.thehookmusic for more information.**

Focus On 

Ruth Murphy

As a primary caregiver to her husband of 31 years, Joe, who was diagnosed with ALS a year and a half ago, Ruth Murphy gained a huge responsibility as she became involved in his medical treatment and home health care while continuing to work full-time.

As Joe's condition only allows him to be out of bed two hours of the day and receive complete assistance with everyday tasks, Ruth must be with him at all times when not at work. Ruth's knowledge as a supervisor has translated into her home life, as she communicates with her son and the home health aide in regards to Joe's needs when she is unable to be with him.

Ruth says of her work as a caregiver, "The sense of life's priorities dramatically changes when accomplishing these goals [of being a caregiver]. But most of all, much of the energy I possess towards this challenge is derived from my empowerment of knowledge and education regarding this complex disease. Attending the ALS sponsored support group meetings and symposia provided me with a wealth of information to enable me to successfully meet this disease head on with confidence."

Ruth is fortunate to have a network of support from friends and family, who have donated such services as a laundry service; once-a-week meals from a neighbor; and a landscaping service. Joe received a wheelchair ramp, made with donated wood, a transfer bench, a lift-chair and table from various friends and co-workers.

"As painful as the diagnosis was, the reality of the ultimate outcome and its impact on our family, I must recognize and appreciate the extraordinary love and devotion shown to us. The generosity and love of friends and family and complete strangers continues to amaze me and make it possible for Joe to face ALS with dignity."

For more information about patient care, contact Patient Services at 800.672.8857. To read about Ruth's experiences in her own words, visit www.als-ny.org.