



ALS Association
Fighting Lou Gehrig's Disease

**Greater New York
Chapter**

The ALS Association Greater New York Chapter

February 2013

Monthly Update

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 • www.als-ny.org

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February Support Groups

NASSAU COUNTY, NY

Sunday, February 3rd - 2 pm to 4 pm
North Shore LIJ - Plainview Hospital
888 Old Country Road, Plainview - Downstairs
Contact: Theresa Imperato, RN, (516) 946-5467
and Jody Wiesel, PhD (917) 699-9751
Topic: Welcome to new Patient Services Coordinator
Cindy Keyser-Posner, LMSW.

SUFFOLK COUNTY, NY

Tuesday, February 5th - 6 pm to 8 pm
Stony Brook University, Dept. of Neurology
179 North Belle Meade Rd, E. Setauket
Contact: Theresa Imperato, RN, (516) 946-5467
Topic: Welcome to new Patient Services Coordinator
Cindy Keyser-Posner, LMSW.

HUDSON VALLEY, NY

Tuesday, February 5th - 6:30 pm to 8:30 pm
Vassar Brothers Medical Mall
Ambulatory Surgery Center - Bldg C - 3rd Floor
200 Westage Business Center, Fishkill, NY
Contact: Helen Mayer, RN, (845) 520-0952
Guest Speaker: Elder care attorney, Allen Feller, Esq.
Topic: New rules on Medicare & Medicaid 2013.

SADDLE BROOK / NORTHERN NJ

Thursday, February 7th - 7 pm to 8:30 pm
Kessler Institute for Rehabilitation
300 Market St., Saddle Brook, NJ
Contact: Debbie Schlossberg, LMSW and
Mary Ann Mertz, RN, (732) 710-8832
Topic: Open discussion.

NEW BRUNSWICK / CENTRAL NJ

Saturday, February 16th - 1 pm to 3 pm
Robert Wood Johnson University Hospital
Medical Education Building, Rm. 108A
180 Somerset Street, follow signs to meeting
Contact: Debbie Schlossberg, LMSW and
Mary Ann Mertz, RN, (732) 710-8832
Topic: Open discussion.

MANHATTAN, NY

Tuesday, February 19th - 6 pm to 8 pm
Phillips Ambulatory Care Center (Beth Israel)
10 Union Square East (b/w 14th & 15th streets)
Neurology Dept- 5th Floor Conference Room
Contact: Jody Wiesel, PhD, (917) 699-9751
Topic: Open discussion.

TELEPHONE SUPPORT GROUPS

Caregivers: Fridays - 11 am to 12 pm
Patients: Fridays - 3 pm to 4 pm
Contact: Sue Zimmerman at (212) 720-3050

The 2013 Walk to Defeat ALS Season is Here!

There's definitely still a chill in the air and Spring may feel far away, but it's already time for the 2013 Walk to Defeat ALS Season! The 2013 Walk to Defeat ALS registration pages will be open for business on February 1st. Following an astounding 2012 Walk season, we are very excited to gear up for this year's Walks. For more details or to register for any of the seven Walks throughout the region, please visit the Walk website: www.ALSWalks.org or call the Special Events team at (212) 619-1400.

Team ALS Joins the 2013 New York City Half Marathon

Team ALS has been selected as a Participating Charity of the 2013 New York City Half Marathon on Sunday, March 17th. If you are interested in applying for one of the available spots or have questions, please contact Kristen Cocoman at (212) 720-3048 or email: Cocoman@als-ny.org. Go here for the application: www.als-ny.org/pdf/2013-half-mara.pdf. Come do the 13 in '13!

Chapter Walk Program Achieves New Milestone

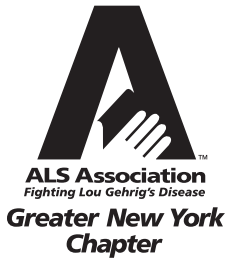
Congratulations once again to all of the PALS, team members, individual walkers, friends and families, and volunteers who participated in the 2012 Walk to Defeat ALS. Your efforts helped to raise a record-breaking \$2 million dollars in the fight to defeat ALS! The Greater NY Chapter is the first ALS Association Chapter to ever achieve this benchmark. Thank you.

RESEARCH NEWS

The pharmaceutical company Biogen Idec reported last month its top-line results of EMPOWER, a Phase 3 trial investigating the drug dexamipexole (Dex) in people with ALS. While Dex showed promise in earlier trials, the latter stage trial revealed certain failures in efficacy that necessitated its discontinuation. Whereas, this is certainly disappointing, such setbacks often allow scientists to build on past research and explore new and better avenues for a cure and effective treatment.

The ALS Association is encouraged that Biogen has made a commitment to continued focus on ALS.

For more information on this research news, please go to als-ny.org.



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f: 212-619-7409
www.als-ny.org

Valentine's Day: Intimacy, Romance & ALS

As Valentine's Day approaches, thoughts of romance and intimacy often ensue. For those couples with a spouse or partner living with ALS, this is a good time to discuss such issues. While the progression of ALS can be cruel on many levels, the possibility of losing the basic human ability to express and receive intimacy is one that doesn't just affect the body, but also the heart and mind.

Sexuality and intimacy are basic human needs. Sexual desires and abilities may not be affected by the disease progression, except for the physical limitations imposed by discomfort, muscle weakness and fatigue or low energy levels. However, emotional reactions to how one's disability affects sexuality can result in inhibitions. Embarking upon previously uncharted territory in your relationship may cause anxiety, inhibiting sexual performance or even basic romantic gestures. The person with ALS may worry about not being able to please a healthy partner or the healthy partner may feel guilt or resentment stopping them from engaging on that level. They may even worry about hurting the person with ALS.

ALS can rob one of so much, but with patience and an open mind, intimacy does not have to suffer. Intimacy in a relationship extends far beyond the bedroom. Simple acts such as listening to music together, dressing up, lighting candles, and caressing are all ways of keeping romance alive. There are any number of creative ways to maintain a level of intimacy that can be both satisfying and allow a relationship to continue to grow.

While muscles may atrophy and motor functions diminish, ALS does not affect one's sensory nerves. Because of this, some wonderful alternative ways to experience sensuality may include holding hands, hugging, touching or massaging one's partner, even when you do not plan to have sex. Engaging in activities that could stimulate all of the senses may make romantic contact more enjoyable.

Honesty and open dialogue with your partner is key. Communicating your likes and dislikes and knowing your partner's likes and dislikes will ease anxiety and help you achieve greater intimacy in your relationship. Speaking with a professional can also help you deal openly with your concerns and expectations.

For a listing of resources, visit our website at www.als-ny.org and look for the February Monthly Update online. Learn about specific tips on intimacy and romance in your relationship.

To speak with a care professional about intimacy and ALS, contact Adele Marano, Director of Patient Services, at (212) 720-3059 or email Marano@als-ny.org.

Happy Valentine's Day to you and yours!

Heart of Giving

Valentine's Day is a day to show your love and support for those who are near and dear to your heart. Making a donation in honor or memory of someone you care about is a great way to do this! Some send flowers or chocolates, but you can also give the gift of hope, so that one day ALS will be a thing of the past. Designate your gift for your loved one today. Visit www.als-ny.org to donate.