



ALS Association
Fighting Lou Gehrig's Disease

The ALS Association Greater New York Chapter January 2009

Monthly Update

Serving Greater New York and Northern and Central New Jersey

116 John Street, Suite 1304, New York, NY 10038, 800-672-8857 f: 212-619-7409 www.als-nj.org

January Support Groups

NEW BRUNSWICK, NJ

January 17, 2008 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: Open Discussion

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

MANHATTAN, NY

January 20, 2008 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

SUFFOLK COUNTY, NY

CANCELLED

(1st Tuesday of every month)
Stony Brook University, Dept. of Neurology
179 Belle Meade Rd, E. Setauket
(631) 444-1970
Facilitator: Theresa Imperato, RN - (631) 444-4623

NASSAU COUNTY, NY

CANCELLED

(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

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

If you haven't been there lately, check out what's new on our website, www.als-ny.org

ALS Association Co-Funds Study About Nerve Cell Loss



In a study that demonstrates a much-anticipated proof of principle, scientists report that raising activity of a natural detoxification system in the body can counteract the progressive loss of nerve cells that characterizes amyotrophic lateral sclerosis (ALS), significantly delaying the onset of disease and extending life.

The research, led by ALS Association-funded scientist Jeffrey Johnson at the University of Wisconsin, was carried out on two different mouse models carrying the human gene for a familial (inherited) type of ALS (Lou Gehrig's Disease) and on cultures of motor neurons at risk of death from the gene.

Studies elsewhere have shown that action of the detox system benefits models of acute injury, such as stroke. This new work, however, reveals that ramping up this system in live animals is effective against a chronic neuron-killing disease such as ALS and that the benefits can occur before its onset.

Johnson's ongoing encouraging studies of the principle in Parkinson's, Huntington's and Alzheimer's disease models suggest its broad application.

The published research also verifies key parts of the protective pathway, suggesting new targets for therapies to come. "Even though we did this study in a mutant mouse model," Johnson says, "this pathway — and the reason it's needed — is the same in humans. That's true, studies show, both in patients with the familial form of ALS or with the more common sporadic form. "We believe that bodes well that our results will apply to ALS in general," Johnson says.

"We are excited about the potential new pathways for ALS therapy suggested in this research," said Dr. Lucie Bruijn, Ph.D., senior vice president for research and development at The ALS Association.

An account of the research appears this week in the Journal of Neuroscience.

FREE Teleconference Explaining Veteran's Benefits For PALS & Their Surviving Spouses.



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VOLUNTEER NIGHT JANUARY 15, 5-7 PM. Contact Christine @ 212-720-3044

Home Modification Program

The ALS Association Greater New York Chapter Patient Services department receives many requests from clinic patients, non-clinic patients and community agencies seeking assistance for their clients. PALS and families request professional assistance in evaluating necessary home modification for PALS to remain in their homes from our Patient Services Department. We developed our Home Modification Program to provide a valuable service to PALS and their caregivers in response to that need.

The need for this program was assessed from many first-hand reports from PALS about having expensive construction work done in their homes with unsatisfactory results. Families had undertaken unnecessarily expensive construction work because they were not knowledgeable about available options. We also were finding that families often spend money on inappropriate equipment for their homes. There was also a general lack of knowledge as to where to turn for financial help to fund a construction project such as this.

Our Assistive Technologist, Antoinette Verdone, ATP (Assistive Technology Practitioner), who has a background in rehabilitation engineering assists PALS and their families to understand their options for home

modifications, which would increase their ability to remain safe and independent at home. Antoinette provides PALS with a home modification assessment including recommendation and/or technical drawings to best accommodate their present and future needs, i.e., installing stair lifts, ramps, elevators, etc. She advises PALS on making their home environment safer regarding obstacles in the home. PALS are informed about products available on the market that



can make their home more accessible without the need for structural modifications to the home. To help fund the cost of the modification, she identifies local resources for home modification funding. The program permits a contractor to receive dimensions from or confer with ATP on specs.

There have been a number of cases where families were planning on doing major renovations. In every case we advised them on changes to the plans to make them more suitable for PALS' needs. The plans that they had were done by contractors that were well meaning, but only referenced government standards. PALS needs are very different from other disabilities. Additionally, many contractors have not had a lot of experience doing modifications for people with disabilities. By being involved at the beginning, it saves families costly mistakes and they can be assured that the modifications will suit the patient.