

Monthly Update



Greater New York Chapter
116 John St., Suite 1304
New York, NY 10038
212.619.1400
fax 212.619.7409
www.als-ny.org

OCTOBER SUPPORT GROUPS

NASSAU COUNTY, NY

October 1, 2006 2:00-5:00 PM
North Shore's Central General Hospital
Old Country Road, Plainview
Downstairs Meeting Room
Switchboard: (516) 719-3000
Topic: Home Accessibility
Facilitators: Theresa Imperato, RN
Jody Wiesel, PhD

SUFFOLK COUNTY, NY

October 3, 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: Home Accessibility
Speaker: Antoinette Verdone
Facilitators: Theresa Imperato, RN
Sheralda Brown-Small,
LCSW

MANHATTAN, NY

October 17, 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: Home Accessibility
Speaker: Antoinette Verdone
Facilitator: Eileen Mullarkey, LCSW

NEW BRUNSWICK, NJ

October 21, 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: Home Accessibility
Speaker: Antoinette Verdone
Facilitators: Debbie Schlossberg MSW, LSW
Mary Ann Mertz, RN

SUPPORT GROUP CONTACT INFO

Theresa Imperato, RN:
Office (212) 619-1400
Pager (516) 335-5454
Eileen Mullarkey, LCSW:
Office (212) 619-1400
Debbie Schlossberg, MSW, LSW:
Mobile (732) 710-8832

Creating an Accessible & Safe Home Environment

Examining one's home environment is extremely important for a newly diagnosed patient. Falls make up nearly half of all home accidents. PALS's level of stability with walking and getting around the home is constantly changing, so if you can provide the broadest level of accessibility, you can relax and PALS can have more freedom.

There are two major rules of thumb when it comes to home modification. Energy conservation is important, and that can be achieved by putting frequently used items within reach, avoiding reaching for items, and sitting for activities whenever possible. Consideration of one's path of travel is also extremely important. One must pick up throw rugs, keep hallways and stairs clear, and make sure paths are lighted.

There are a number of simple solutions to make one's home an accessible environment. Look around and see what minor details can pose a problem, and use the tips listed below as a guide for modifying your home.

1. Doorway thresholds that are more than 1/2 inch tall should be ramped.
2. For accessibility, doorways should have a 32 inch clear width. Use offset or swing away hinges as to help uphold that clearing.
3. Invest in lever handles and key turners to make unlocking and opening doors much easier. A person who has a tendency for the high-tech lifestyle can easily open locked doors using infrared technology. For more information, visit: www.smarthome.com.
4. Installing handrails can be helpful with getting around. Be sure that there is no more than 1 1/2 inches between the wall and the inside of the handrail.
5. The use of a hand held shower head with an on and off switch makes bathing an easier task.
6. Invest in a shower seat or tub transfer bench to help conserve energy while bathing.

For those that need more than a simple solution in creating a safe home environment, several companies offer non-invasive products to make getting around the home easier.

1. For bathing, a tub slider allows PALS to roll directly over the commode to use the bathroom, as well as shower. The chair rolls over to the bathtub and the entire seat can slide over the bathtub, making bathing a less stressful experience. For more information, visit: www.pvcme.com.
2. For those who can no longer use traditional bathing facilities, www.fawssit.com offers a self-contained portable shower stall that can be used any where there is access to warm water, a drain, and an electrical outlet.
3. A Stair-Trac allows wheelchairs to get up and down steps without having to install a ramp. The Stair-Trac is slipped under the wheelchair and rubber tracks attach to a motor to lift the chair up the steps with ease. Visit www.garaventa.ca for more information.
4. A Voyager or Easy Track makes lifting a simpler task for family members and caregivers. Using tension, the Easy Track can be installed without doing damage to the home. This device has a track along the ceiling. A sling is used to transfer the patient, similar to a hoist lift. This device can be found at www.sunrisemedical.com.

Sometimes permanent home modifications need to be made. Common modifications include a ramp to get in and out of the home, lifts to get up and down steps, and a roll-in shower. The Greater New York Chapter offers a Home Visit Program, so our Assistive Technology Specialist, Antoinette Verdone, can examine your needs before making any home modifications.

There aren't many financial resources offered for general home modifications. Basic items like swing away hinges and lever door knobs are inexpensive, but more intricate modifications can be costly. While insurance will fund basic items such as a hospital bed and a commode, one must look elsewhere for funding for other items. Sources of funding could be Long Term Care insurance or Vocational Rehabilitation. Veterans Affairs and Rural Development offer grant opportunities. Visit www.homemods.org for more information about grants for home modification. The Greater New York Chapter has some limited items for home modification through the Jon Stone Equipment Loan Program.

For more information about the Jon Stone Equipment Loan Program or the Home Visit Program, please contact Antoinette Verdone at 800.672.8857 or visit the Patient Services section of www.als-ny.org.



Greater New York Chapter
 116 John St., Suite 1304
 New York, NY 10038
 212.619.1400
 fax 212.619.7409
 www.als-ny.org

Non-Profit Org.
 U.S. Postage
 PAID
 New York, N.Y.
 Permit No. 7566

VOLUNTEER NIGHT October 12th 5-7 PM Contact Chris @ 212.720.3044

Opportunities  and Announcements

Dr. Lucie Bruijn, The ALS Association's science director and vice president of research, has been appointed to the advisory council of the National Institute of Neurological Disorders and Stroke (NINDS). The appointment of Bruijn onto this major governmental healthcare organization is based on her scientific credentials and requires that she make recommendations not only in the ALS field but more broadly. The appointment also is an acknowledgement of Dr. Bruijn's outstanding leadership and work in the field of neuroscience in general and ALS in particular. Please visit www.als-ny.org for more information about Dr. Bruijn's appointment.

Thank you to WPST DJ, Mike Newman, for supporting The ALS Association in City of Trenton's Department of Recreation's Celebrity Charity Scrabble Tournament on September 23rd. DJ Newman joined Congressman Rush Holt; Trenton City Councilman, Jim Coston; The Trentonian columnist, Jeff Edelstein, and other local celebrities competing for almost \$2,000 to go to their charity of choice.

Thank you again to all Walkers for helping to make our 2006 Walk season a success! We have passed our Spring 2005 total by 35% and donations keep coming in. Thank you to Bagel Boss for donating all the bagels, butter and cream cheese for the Long Island Walk, and Applebee's for supplying hot dogs and snacks after the Walk. Many thanks to North Fork Bank for promoting the Walk and selling feet in all 200 branches in Nassau, Suffolk, Brooklyn and Queens.

Calendar of  Events

October 19 - Make Me A Plate, A Long Island Tasting Event from 7:00 p.m. to 11:00 p.m. at Leonard's in Great Neck, NY. For more information visit www.addingloveandsupport.org, or email info@addingloveandsupport.org

October 22 - Theater Matinee, *Mary Poppins*. For tickets call Shelley Finkelstein at 212.750.9154.

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 call Jenn Lowy at 800.672.8857.

November 8 - Theater Night, *Jersey Boys*. For tickets call Shelley Finkelstein at 212.750.9154.

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

December 6 - Theater Night, *The Times They Are A-Changin'*. For tickets call Shelley Finkelstein at 212.750.9154.

Focus On 

Beverly Cotrone

When Beverly Cotrone's husband, Joe, passed away from ALS in 2004 after having lived for over three years with the disease, she jumped head-first into her involvement with The ALS Association Greater New York Chapter.

Since 2001, Beverly has been a Captain of the Long Island *Walk to D'Feet ALS* team, Kent's Lodge. She has been a member of the Long Island *Walk* Committee for 2 years, taking a role in planning and organizing our nation's largest *Walk*. Says Beverly of the *Walk*, "The *Walk* is a great way to raise awareness, but most importantly it provides great networking opportunities between family and friends. It also provides a means for PALS to share experiences and stay in touch with updates on research."

Beverly's fundraising for ALS doesn't stop when the *Walk* season ends. Beverly introduced a "50-50" Raffle in her neighborhood, which has now become a Fourth of July tradition. Says Beverly about her fundraising efforts, "The reason for the success of the Raffle is because each year folks wait for the opportunity for a chance to win extra cash and at the same time donate to The ALS Association in honor of Joe . . . The key to fundraising success is to reach out with your heart and you will be surprised at the results."

Beverly has also become involved in ALSA's advocacy efforts. In March 2006, she attended New York's first-ever State Advocacy Day for ALS. Meeting with her State Senator, Serphin Maltese (D-15) and Assemblywoman, Audrey Pfeffer (D-23) allowed Beverly the opportunity to participate in educating the New York State Legislator about ALS and the effects it has on their constituents. Says Beverly about advocacy efforts, "Knowledge is power and government officials need to be aware of the challenges and experiences faced with this devastating disease. There is no better voice than that of PALS and their families. The power of our voice can bring us closer to the day we find a cure for ALS."

For more information about fundraising, contact Jenn Lowy or for more information about advocacy, contact Kate McNamee at 800.672.8857