

The ALS Association Greater New York Chapter

January 2012

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

January Support Groups

SUFFOLK COUNTY, NY

January meeting CANCELLED
Next meeting will be Tuesday, February 7, 2012
Details in next Monthly Update.

NASSAU COUNTY, NY

January meeting CANCELLED
Next meeting will be Sunday, February 5, 2012.
Details in next Monthly Update.

HUDSON VALLEY, NY

Tuesday, January 3rd - 6:30 pm to 8:30 pm
Ambulatory Surgery Center - Bldg C - 3rd floor
200 Westage Business Center, Fishkill, NY
Contact: Helen Mayer, RN, (845) 520-0952
Topic: Open Discussion
** Massage Therapist Max Cohn will be onsite
donating massages for both PALS & caregivers**

MANHATTAN, NY

Tuesday, January 17th - 6 pm to 8 pm
Phillips Ambulatory Care Center (Beth Israel)
10 Union Square East (b/w 14th & 15th streets)
2nd Floor- Conference Room #1
Contact: Jody Wiesel, PhD, (917) 699-9751
Speaker: Betsy Thomason, Respiratory Therapist

NEW BRUNSWICK / CENTRAL NJ

Saturday, January 21st - 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

ATTENTION: A **NEW** Saddle Brook/Northern NJ
Support Group will be forming starting February 2nd.
For details contact Debbie Schlossberg, (732) 710-8832.

TELEPHONE SUPPORT GROUPS

Caregivers: Wednesdays - 11 am - 12 pm
Patients: Wednesdays - 3 pm - 4 pm
Adult children of PALS: Friday - 11 am - 12 pm
Contact: Sue Zimmerman at (212) 720-3050

Go Green!

Do you receive the paper version of the Monthly Update in the mail? Do you have an email address? If you answered yes to both questions, please help The Greater New York Chapter GO GREEN! Help us to save on printing & postage costs while ensuring we use less paper each month. The email version of the Monthly Update has more information and articles, including pictures and videos, and it won't get lost in the mail. Each penny saved can be redirected to patient services programs. Call us today at (212) 619-1400 and tell us to send you the Monthly Update via email. The Greater New York Chapter and the environment thank you.

This is the Year You Create Your Legacy

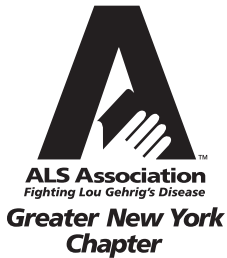
The beginning of a New Year is the best time to assess your financial situation. It's also a good time for valued friends of the Chapter to consider making a planned gift to The ALS Association Greater New York Chapter.

Gifts that anyone can afford: A bequest in your will or living trust naming The ALS Association Greater New York Chapter as a beneficiary of your retirement plan, or a gift of life insurance are all ways to create your legacy in the fight against ALS while maintaining your current lifestyle and your family's security.

Gifts that pay you income: A charitable gift annuity gives back in the form of fixed annual payments guaranteed to you and your spouse for life, as well as a charitable income deduction. A deferred charitable gift annuity also provides you with an immediate income tax deduction and you can designate your annuity payments to begin when you need them, such as retirement or when a grandchild needs help with tuition payments.

Información en Español

The Greater New York Chapter website now has information on ALS and Chapter services in Spanish. If you know someone with ALS who may need information in Spanish, please refer them to - www.als-ny.org/espanol.



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Getting Started with Communication

by Ben Lieman

The eyes may be the window to the soul, but it sure helps to clarify with a voice, what we say with our eyes. There are options available when the voice is too soft or simply unable to be understood. This article will help explain the simple, low-tech options that are currently out there. There are also high-tech solutions that may be covered by insurance and Medicaid, and can be operated with minimal movement of hands, fingers, head, or even just eye-movement. An evaluation for this equipment is necessary, and we are happy to share information about this equipment, and where to obtain an evaluation. These high-tech options provide very good computerized voice output in English, Spanish, and other languages. They also enable computer and internet access, again with minimal body movement or even just eye movement.

But there are also simple solutions that can be set up with no or little technology. It won't get you on the internet, but it will enable communication immediately. An involved listener is essential as these low-tech methods do not store messages for later use. Communication with this method is done in real time.

1) **Communication Boards** can be a sheet of paper, cardboard, lightweight plastic that has communication options on the page. Letters, or pre-printed words and phrases can be identified by pointing with a finger (or pointing object like a pen or wrist cuff). With letters, you can spell out anything. With words or statements, you can easily communicate a simple request (How are you?, Raise my leg, I'm thirsty, Who called?, etc.).

Communication boards can be obtained online (there are numerous options available) or created with any word processing program. The key component is that the letters or messages on the communication board are easy to read, and differentiated by enough space so pointing does not need to be precise.

2) **Laser Pointers** (i.e. key chain or presentation) utilize a pinpoint light generated to point to the letters or messages on a pre-written communication board. They can be velcro-ed to a head band or baseball cap, and highlight choices with small head movements. (Be sure to avoid pointing at someone's eyes.) Some small LED flashlights accomplish a similar effect with a narrow beam of light. The beam of light generated must be narrow (1 inch diameter or less) at a distance of 1-2 feet (where a communication board is held).

To view the full article and learn more about other assistive technological devices, go to our website at www.als-ny.org and click on the latest newsletter.

With a little patience, these methods can provide a good means of communication right away, while you consider or apply for higher tech solutions. If you have questions about any of these or other low- and high-tech forms of communication, please contact the Chapter office at (212) 619-1400 and ask for Ben Lieman, Assistive Technology Specialist.

Be Prepared. This is not just a Boy Scout credo, but welcome words to live by, particularly if you are living with ALS. As the Winter months are now upon us, we must prepare ourselves for snow and blizzards. Please review the ALS Emergency Preparedness list to prepare your homes and equipment in case of a blizzard. We know last Winter was a rough one that left many people without power and unable to leave their homes. Let's be sure to brave the possible storms, remain safe and warm, and ensure our health is not adversely impacted by bad weather.

To view the list of emergency preparedness tips, go to our website at www.als-ny.org and click on the latest newsletter.