



The ALS Association Greater New York Chapter

January 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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Happy New Year from the Board & Staff of The ALS Association Greater New York Chapter!

January Support Groups

SUFFOLK COUNTY, NY

Tuesday, January 8th - 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: Open Discussion

HUDSON VALLEY, NY

January meeting cancelled.

Will meet in February.

Contact: Helen Mayer, RN, (845) 520-0952

SADDLE BROOK / NORTHERN NJ

Thursday, January 3rd - 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

NASSAU COUNTY, NY

Sunday, January 6th - 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: To be announced.

MANHATTAN, NY

Tuesday, January 15th - 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: New info about Medicare & Medicaid
Speaker: Julia M. Greenberg, Attorney

NEW BRUNSWICK / CENTRAL NJ

Saturday, January 19th - 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: A PALS Research update w/ Dorothy Smith

TELEPHONE SUPPORT GROUPS

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

Double Impact

With 2012 now a memory, we would like to take this time to say THANK YOU to all of our Chapter supporters. Your donations have enabled us to provide services to almost 700 PALS and their families in the Greater New York area last year. Your generosity also funded a number of cutting-edge ALS research projects that may move us another step closer toward a cure for ALS. We couldn't have done it without you and we are extremely grateful!

But did you know your gift could be doubled this year? This new calendar year is a great time to check if your company matches your charitable donations. Many companies have a corporate matching program that allows you to donate to The ALS Association Greater New York Chapter and after filling out a simple form, that donation is matched by your company. If you don't know your company's policy, your HR department should have all the answers you need!

It's never too early to start to plan your financial gifts for the year. Your giving can provide our PALS and their families with the most comprehensive support throughout the year. Help us double the impact today!

@sk Ben...

My husband was recently diagnosed with ALS. We are considering a stair glide to go up and down the stairs in our home. How long do you think he will be able to use it? - Arlene - Westchester County

The best answer is... it depends. A stair glide provides access to another floor, when walking up or down is no longer safe or possible. Safe stair glide use depends on the rider's ability to sit independently and maintain upper body balance. A seat back, arm rest, foot plate, and seat belt all provide assistance in this process. If the user finds themselves leaning over an armrest unable to sit upright, or requires a tilted seat or harness in order to do so, then a stair glide seat may not provide enough support. Some caregivers will walk up or down the steps, alongside the rider, to support them. However this is not recommended and it could be potentially unsafe for both individuals.

As with many products that provide assistance, it is important to use them safely and consider other options when necessary. We unfortunately do not accept stair glides in our warehouse, but we can provide you a list of dealers in the New York/New Jersey area. We recommend using a dealer to provide the best installation, as well as a warrantee. You could also post a request on our Chapter Facebook page and get feedback from others in our area on what's worked best. - Ben

To ask Ben a question, simply email him at blieman@als-ny.org or call at (212) 720-3057. Ben will answer all questions directly as usual, but not all questions will appear in the Monthly Update.



Greater New York Chapter
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New Year's Resolutions

The ball in Times Square has dropped, Auld Lang Syne has been sung, and Baby New Year has ushered in 2013. And as is tradition with so many cultures around the world, now is the time to make New Year's resolutions. Here are 12 resolutions you can do (one per month) to help fight ALS all year round:

Donate - Make a gift to The ALS Association Greater New York Chapter and remember to check if your company offers matching gifts.

Volunteer - Help people living with ALS and their caregivers with simple tasks to improve their lives. You can also volunteer at one of the several events the Chapter holds each year, including the Walks to Defeat ALS.

Advocate - Join us in Washington, DC in May and advocate about ALS related issues to your Senators and Member of Congress. If you can't make it to Washington, sign a letter to your representatives showing your support for more ALS government funding and the ease of obstacles to research.

Write a Letter - Write a Letter to the Editor of your local newspaper and raise awareness about ALS in your community. Or you could even blog your story. Share it with us and we could post it on the Chapter blog as well. Tell your story from the heart and get it published.

Social Media - If you're on Facebook or Twitter, join one of the numerous platforms the Chapter provides and stay connected between Monthly Updates. There's a community of over 5,600 on Facebook & Twitter throughout the region. Be a part of it.

Walk - Join us for the ALS Association's signature fundraising event - the Walk to Defeat ALS. There are six Walks throughout the region. Find one near you. Registration for the 2013 Walks begins on February 1st. Visit alswalks.org for more details. Every step makes a difference.

Community Events - Plan an event in your community to raise funds and awareness for ALS. Whether it is a bake sale at a school, a rummage sale at your church, a poker night at your

home, or a happy hour at a bar or restaurant, you can organize an event in your community that suits you. If you are athletic and already participate in an existing event (i.e. NYC Marathon, 5 Borough Bike Tour, half marathon, local 10K, etc...), you can be a part of Team ALS. Help raise funds and awareness for research & patient services through any event that you participate in or organize. We have a team of people here to support you. Email Kristen Cocoman at Cocoman@als-ny.org for more information.

Financial Planning - Include the ALS Association Greater New York Chapter in your will, donate securities to the Chapter, or take advantage of our planned giving program. There are also a number of other creative and financially sound ways to make a gift than simply writing a check. Check into it.

Register - If you're living with ALS, you should register with the National ALS Registry and complete the surveys so the Centers for Disease Control & Prevention can better understand the nature of ALS and bring us one step closer to a cure. If you know someone living with ALS, help them to register if they need it.

Take in a Game - Throughout the summer, the ALS Association teams up with Minor League Baseball to raise awareness for ALS throughout the country. Look for an ALS Awareness Day with the MiLB team nearest you and head out to the ballgame. ALSA is an official Charity Partner of Minor League Baseball.

Wear it and Share it - You can raise awareness for ALS through fashion or on your car. Purchase a stylish ALS awareness bracelet or don a bumper magnet for your car and raise awareness for ALS with those you pass by every day.

Talk about it - Whether you're living with ALS or know someone who is or has, tell your story to your friends, colleagues, fellow congregants and make your ALS story heard. The more people know about ALS, the more understanding we can generate and the more hope we can provide. It can be very painful to talk about, but your voice is needed to help spread the word.

If you do all twelve resolutions, or even just one, you will make a difference. If you need any help along the way, the staff of the ALS Association Greater New York Chapter is here to assist you and get you started. Call us at (212) 619-1400 or email als@als-ny.org and we'd be happy to discuss ways for you to get involved in the fight against ALS. Happy New Year!