



**Greater New York Chapter**

1994 · 20th Anniversary · 2014

The ALS Association Greater New York Chapter

February 2014

# 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

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## Save the Dates – 2014 Walks to Defeat ALS

- NYC: Saturday, May 3 • Long Branch, NJ: Sunday, May 18 • Saddle Brook, NJ: Sunday, June 8 • Westchester, NY: Saturday, June 14
- Somerset, NJ: Saturday, June 21 • Long Island, NY: Saturday, Sept. 20 • Hudson Valley, NY: Sunday, Oct. 19

## FEBRUARY SUPPORT GROUPS

### NASSAU COUNTY, NY

Sunday, February 2nd - 2 pm to 4 pm  
North Shore LIJ - Plainview Hospital  
888 Old Country Rd., Plainview - Downstairs  
Contact: Theresa Imperato, RN, (516) 946-5467  
& Cindy Keyser-Posner, LMSW (631) 416-2767  
Topic: ALS - Healthy Eating & Supplements  
Guest speaker: Lorraine Danowski, RD  
*Next month's support group meets March 2nd.*

### SUFFOLK COUNTY, NY

Tuesday, February 4th - 6 to 8 pm  
Stony Brook University, Dept. of Neurology  
179 N. Belle Meade Road  
East Setauket, NY  
Contact: Theresa Imperato, RN, (516) 946-5467  
& Cindy Keyser-Posner, LMSW (631) 416-2767  
Topic: ALS - Healthy Eating & Supplements  
Guest speaker: Lorraine Danowski, RD  
*Next month's support group meets March 4th.*

### HUDSON VALLEY/FISHKILL, NY

Tuesday, February 4th - 6:30 to 8:30 pm  
Ambulatory Surgery Center  
Building C - 3rd Floor  
200 Westage Business Center, Fishkill, NY  
Contact: Helen Mayer, RN, (845) 520-0952  
Topic: Open Discussion  
*Next month's support group meets March 4th.*

### NORTHERN NJ/SADDLE BROOK

Thursday, February 6th - 7 to 8:30 pm  
Kessler Institute for Rehabilitation  
300 Market Street, Saddle Brook, NJ  
Contact: Debbie Schlossberg, LMSW  
and Mary Ann Mertz, RN, (732) 710-8832  
Guest speaker: Betsy Thomason, BA, RRT,  
Respiratory Therapist  
*Next month's support group meets March 6th.*

### WESTCHESTER, NY/WHITE PLAINS

Tuesday, February 11th - 6 to 8 pm  
Burke Rehabilitation Center  
785 Mamaroneck Avenue, Main Hospital  
Bldg 7, 1st Floor, Conference Rm G-41  
White Plains, NY  
Contact: Helen Mayer, RN, (845) 520-0952  
Guest speaker: Erika Mayer, MS L-CAT,  
RYT and Deb Brass MS,CAT-LP.  
Topic: Art Therapy  
*Next month's support group meets March 11th.*

### CENTRAL NJ/NEW BRUNSWICK

Saturday, February 15th - 1 to 3pm  
Rutgers Robert Wood Johnson Medical School  
Medical Education Building  
Room 108A, 180 Somerset Street  
Follow signs to meeting  
Contact: Debbie Schlossberg, LMSW and  
Mary Ann Mertz, RN (732) 710-8832  
Topic: Open Discussion  
*Next month's support group meets March 15th.*

### MANHATTAN, NY

Tuesday, February 18th - 6 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: Role of Caregivers in a patient's life  
and open discussion  
*Next month's support group meets March 18th.*

## TELEPHONE SUPPORT GROUPS

For caregivers and patients.

Patient group - every Friday from 3pm to 4pm.  
Caregivers group - every Friday from 4pm to 5pm.  
Contact: Sue Zimmerman, LCSW at (212) 720-3050

## Upcoming Events

2/13 - YPG Valentine's Day Happy Hour. 6:30pm to 9 pm at Brinkley's NYC, 406 Broome St., NYC.  
For info: Loren Domilici at (212) 720-3060.

2/28 - 8th Annual Big Ed Benefit for ALS. Hudson Station Bar and Grill, 9th Ave. (at 35th Street.), NYC. For info: Ally Davis at (212) 720-3049.

3/16 - Team ALS will once again be Running 4 A Cure in the New York City Half Marathon!  
For more info on how you can support Team ALS, call Kristen Cocoman at (212) 720-3048.



Walk to  
Defeat ALS®  
The ALS Association

Registration for the 2014 Walk to Defeat ALS season will be open on February 1st!

Visit [www.ALSWALKS.org](http://www.ALSWALKS.org) to register for a Walk near you this year!



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42 Broadway, Suite 1724  
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## THE POWER OF LOVE COMES THROUGH FOR MOM

For the Mendez family, love - and a little bit of assistive technology - has helped them to overcome one of the obstacles ALS has put in their way: Communication.

Alexander Mendez is a tech-savvy guy who, according to his mother Carmen, was good at computers, loved to play X-Box and talk to his friends about their shared interest in gaming.

"He's very smart," Carmen said of her son. "Intelligent."

But since being diagnosed with ALS, Alexander has slowly lost the ability to play his games, use his computer, and work at his job as a medical technician sterilizing surgical instruments. As his mother points out, like most ALS patients, he's still as mentally acute as ever.

"He remembers his computer skills," she said.

Having lost the ability to speak, Alex communicates with his family through facial gestures and blinking to signal yes or no.

"We had to figure out the right questions to ask him and sometimes it could take 20 minutes or more to determine what Alex was saying," said his mother.

Caring for Alex at home became too much for Carmen, and nine months ago he was admitted to a nursing home. Carmen visits with him everyday, and communication was always a challenge. She says it was Daniel, Alex's step-brother, who first contacted The ALS Association Greater New York Chapter.

He said "they have a device to help Alex communicate." It was an eye-tracking device that moves a cursor around the screen, when someone moves their eyes.

Ben Lieman, ATP, MSW, Assistive Technology Specialist for the Chapter, was able to match Alex with a Dynavox Eye-Max from our equipment loan closet. The device allows Alex to look at specific letters to spell out what he wants to say. There is a speak button that he can look at too, so the device "speaks" the words.

"Alex and I were so anxious for it to get here," said Carmen. "Finally something to help him communicate with me."

On a recent afternoon, Ben helped get Alex set up. His family was there when he first used the device, and almost immediately, he was able to create a simple message.

"The first thing he said was, 'I love you Mom,'" said Carmen.

Getting used to the device was a little tricky but his mother says he's improving his skills every day.

"He has to master how to use it," she said. "He's trying. It's excellent."

The communication device has opened up a new world for Alex. Now, his family is trying to get him onto the Internet so he can look up websites, do some reading, write emails and, according to his mother, possibly hook up with some old buddies online.

"He might be able to communicate with friends he made while playing games," she said.

The ALS Association Greater New York Chapter was there when the Mendez family needed the help. And with a simple message of love, a patient was able to do something many of us have the ability to do every day: Tell those close to us that we love them.

Carmen said that she is very grateful for opportunity to communicate with Alex again. She called it a "Godsend." Alex is happy too.

"Every time we ask, he says he loves it," she said.

To donate gently used assistive technology equipment or for more information about The ALS Association Greater New York Chapter's Assistive Technology Loan Program, please contact Ben Lieman, ATP, MSW at (212) 720-3057 or email [blieman@als-ny.org](mailto:blieman@als-ny.org).

### *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!

You can 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](http://www.als-ny.org) to donate or contact Loren Domilici at (212) 720-3060 or [ldomilici@als-ny.org](mailto:ldomilici@als-ny.org).