



ALS Association
Fighting Lou Gehrig's Disease

**Greater New York
Chapter**

The ALS Association Greater New York Chapter

September 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

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September Support Groups

NASSAU COUNTY, NY

Cancelled for September. Next Meeting on Oct. 7th.

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

SUFFOLK COUNTY, NY

Tuesday, September 4th - 6 pm to 8 pm
Stony Brook University, Dept. of Neurology
179 North Belle Meade Rd, E. Setauket
Topic: Open Discussion
Contact: Theresa Imperato, RN, (516) 946-5467

HUDSON VALLEY, NY

Tuesday, September 4th - 6:30 pm to 8:30 pm
Vassar Brothers Medical Mall
Ambulatory Surgery Center - Bldg C - 3rd Floor
200 Westage Business Center, Fishkill, NY
Topic: Walk to Defeat ALS
Speaker: Allison Lardner, ALS Association GNY Chapter
Contact: Helen Mayer, RN, (845) 520-0952

SADDLE BROOK / NORTHERN NJ

Thursday, September 6th - 7 pm to 8:30 pm
Kessler Institute for Rehabilitation
300 Market St., Saddle Brook, NJ
Topic & Speaker: To Be Announced
Contact: Debbie Schlossberg, LMSW (732) 710-8832

MANHATTAN, NY

Note: Temporary Date Change

Tuesday, September 11th - 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
Topic: Open Discussion
Contact: Jody Wiesel, PhD, (917) 699-9751

NEW BRUNSWICK / CENTRAL NJ

Saturday, September 15th - 1 pm to 3 pm
Robert Wood Johnson University Hospital
Medical Education Building, Rm. 108A
180 Somerset Street, follow signs to meeting
Topic: "The Emotional Rollercoaster of Life with ALS"
Speaker: Dale Ofei-Ayis, University of Behavioral Health
Contact: Debbie Schlossberg, LMSW and
Mary Ann Mertz, RN, (732) 710-8832

TELEPHONE SUPPORT GROUPS

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

Note: June through September, telephone support groups will occur bi-weekly, with this month's meetings occurring on September 14 & 28.

September 9th is **National Grandparents Day**. We take this time to reflect on grandparents, particularly those impacted by ALS. Share with us a story of your grandparents. Visit our Facebook page at facebook.com/ALSofGNY and post a short story or picture. Thank you to all the grandparents past and present who've touched our lives so deeply. Here is a story from one of our ALS advocates reflecting on his special relationship with his grandfather.

Someone To Look Up To

by Peter John Vinci

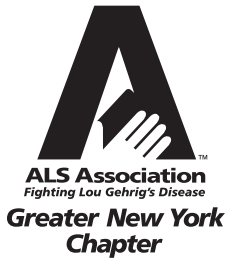
For a number of years now, my father, aunt and I take a trip to Washington, DC for National ALS Advocacy Day in May. And each year I talk about one of the most abiding influences in my life – my grandfather. As many know, our nation's military veterans are twice more likely to develop ALS than civilians. My grandfather, who was wounded in Pearl Harbor, was not just a war hero, but my personal hero. He was bigger than life...that is until he got ALS. This towering man in my life became completely dependent on others and sadly died in a shell of a body that did not reflect his outsized personality.

"I was lucky to have known him." I think this was something most people who met my grandfather would say. Benjamin Vinci was born in Port Chester, NY on April 16, 1919. He and I were born on the same date, April 16th. We spent every birthday together – 29 of them in all. He always had more candles than me but made me feel like I was the special one. Near the end of his life, I had to blow out the candles for both of us, as ALS robbed him of this simple pleasure.

Grandpa was shot by a Japanese Zero airplane at Pearl Harbor, December 7, 1941, a day that lived in infamy for the nation and for him personally. He was one of the first to be injured in the attack. Two bullets pierced his body and he was given up for dead. He would later wake up the next day in the morgue. Medics on the island were unable to operate on him, so he was transferred. He was placed on a boat from Pearl Harbor to San Francisco and finally to Denver, Colorado's Fitzsimmons Hospital where he was finally operated on by some of the best surgeons. After 9 long hours on the operating table doctors were still unable to remove one of the bullets, so he had to live with it for the rest of his life. Even after his long recovery and serious condition he refused a discharge and remained in the Army until 1943. From that time on, Grandpa treasured every bit of life.

After returning to civilian life he met my grandmother, Rose Civitella at the bowling alley. Grandma Rose threw the ball down the wrong alley and into Grandpa Ben's alley. He would tease her and say, Rose you did it on purpose to meet me and Grandma said oh no, I was a lousy bowler. They fell in love, married, built their own house, and had four children - my father, Peter, my two Aunts Jo-Ann and Bernadette, and my Uncle Joseph. I was the first, and lucky for me, the only grandchild. Being the only grandchild I was blessed to have Grandpa all to myself. We all lived in the same two-family house in Port Chester, NY.

To view the entirety of Peter's story about his grandfather with ALS, go to www.als-ny.org and click to see the latest newsletter.



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f: 212-619-7409
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Team ALS – We’re Back & Bigger, Better, Stronger than Before!

The Chapter’s Team ALS: Running 4 A Cure is once again participating in the ING New York City Marathon. On Sunday, November 4th, sixteen members of TEAM ALS will take to the streets of New York City’s five boroughs to raise funds and awareness for ALS. Each breath will breathe life into innovative ALS research. Each step will help a patient who can no longer take one on their own. Crossing the finish line will bring hope to thousands.

To learn more about the ING Marathon team, visit www.web.alsa.org/goto/teamals2012.

But there’s even more exciting news! This year Team ALS doesn’t just begin and end with the NYC Marathon. While it is the pinnacle of endurance for many runners, it’s not the only way to take strides to defeat ALS. After receiving overwhelming interest from other runners, we have officially expanded TEAM ALS: Running 4 A Cure so that runners of all levels and locales can become part of our Team!

To learn more, visit the expanded website at www.web.alsa.org/goto/teamals.

Walk to Defeat ALS - The Chapter's BIGGEST Walk is here!

The Long Island Walk to Defeat ALS is the Chapter's oldest Walk and the nation's biggest and it's just a few weeks away! Join us on Saturday, September 29th at Eisenhower Park in East Meadow, Long Island. It's not too late to register! www.alswalks.org

Also get ready for the scenic Hudson Valley Walk on Saturday, October 21st on the Walkway Over the Hudson. Check the website for details.

It's National Chicken, Potato, & Mushroom Month

by Lorraine Danowski, Registered Dietician, ALSA Center at Stony Brook Hospital

In September we honor a number of foods, including chicken, the potato, and the mushroom. Here is a recipe that combines these three powerful foods that are delicious, healthy, and easy to eat for people with ALS.

Potatoes provide the body with much-needed calories and fiber. Cheese, skim milk powder, butter, and whole milk may make this starchy vegetable a terrific source of calories and some protein. Mushrooms provide vitamins and minerals while adding a “meaty” quality to foods. Chicken (as well as fish, beef, pork, eggs, cheese and milk) provides protein that supports muscles, including respiratory muscles. Each one ounce of chicken provides 7 grams of protein. You should aim for a minimum amount of 60 grams of protein per day.

Here's an easy recipe you can make at home:

Chicken Meatballs & Mashed Potatoes

- 1/4 cup (c.) plain bread crumbs
- 3/4 teaspoon salt
- 3/4 teaspoon freshly ground black pepper
- 1 pound ground chicken
- 1/2 cup chopped fresh spinach
- Olive oil
- 2 large eggs, lightly beaten
- 1/2 c. chopped mushrooms
- 1 tablespoon plus a 1/2c. whole milk
- 4-5 medium potatoes
- 1 tablespoon ketchup
- 4-5 teaspoons of butter
- 3/4 cup grated parmesan cheese
- Chicken stock

In a medium bowl, stir together the bread crumbs, spinach, eggs, milk, ketchup, parmesan cheese, mushrooms, and the salt & pepper.

Add the chicken and gently stir to combine. Use a small melon ball to shape meatballs into uniform pieces.

In a large (14-inch) skillet, heat the oil over medium-high heat. Working in batches, add the meatballs and cook without moving until brown on the bottom, about 2 minutes. Turn the meatballs over and brown the other side, about 2 minutes longer. Place in oven set at 375 and bake until cooked through. Place chicken stock in skillet and heat through.

In a large pot of salted, boiling water peel, slice into 1 3/4 inch pieces and cook potatoes until tender, about 20 minutes. Place in mixer with 1/2 c. milk, 4-5 teaspoons of butter and blend. Salt & pepper to taste.

Cover meatballs with reduced chicken stock.