



ALS Association
Fighting Lou Gehrig's Disease

The ALS Association Greater New York Chapter

Monthly Update

Serving Greater New York and Northern and Central New Jersey

42 Broadway, Suite 1724, New York, NY 10004, 212-619-1400 f: 212-619-7409 www.als-ny.org

July Support Groups

NASSAU COUNTY, NY

CANCELLED DUE TO
JULY 4TH HOLIDAY

North Shore's Central General Hospital
888 Old Country Road, Plainview
Downstairs Meeting Room; (516) 719-3000
Facilitators: Theresa Imperato, RN - (631) 444-4623
Jody Wiesel, PhD - (917) 699-9751

SUFFOLK COUNTY, NY

July 6, 2010 6:00-8:00 PM
(1st Tuesday of every month)
Stony Brook University, Dept. of Neurology
179 North Belle Meade Rd, E. Setauket
(631) 444-1970

**Topic: Enjoying The Summer BBQ
& Walk to Defeat ALS**

Speaker: Allison Lardner, Walk Manager
Facilitator: Theresa Imperato, RN - (631) 444-4623

NEW BRUNSWICK, NJ

July 17, 2010 1:00-3:00 PM
(3rd Saturday of every month)
Robert Wood Johnson University Hospital
Medical Education Building, Rm 108A
180 Somerser Street, Follow signs to meeting.

Topic: Open Discussion.

Facilitators: Debbie Schlossberg, LMSW
(732) 710-8832
Mary Ann Mertz, RN

MANHATTAN, NY

July 20, 2010 6:00-8:00 PM
(3rd Tuesday of every month)
Phillips Ambulatory Care Center (Beth Israel)
10 Union Square East (Bet. 14th & 15th St.)
2nd Floor, Conference Room #1

**Topic: Equipment Help For
The Patient & Caregiver.**

Speaker: Carole Bishop, RN
Facilitator: Jody Wiesel, PhD - (917) 699-9751

For more information about our Support Groups
go to the Patient Services section at:

2010 Long Island Walk to Defeat ALS Kick-Off Cocktail Party, Wednesday July 14th

Join us on Wednesday, July 14th, 6:30 pm at Westbury Manor to receive your 2009 Walk award, pick up your Walk promotional materials and learn about new fundraising tips to make the 2010 season the most successful year yet!!

To RSVP contact Allison or Rebecca at (212) 619-1400 or walk@als-ny.org.
Please RSVP by July 12th with the number of people that will be attending.

Long Island Walk to Defeat ALS Sunday, September 26th



Enjoying the Summer Bar-B-Que!

Summer 2010 is upon us and the smell of steaks on the grill and the sound of water splashing in the pool is all around us. Invitations to join friends and family for shish-kabob and s'mores may start coming in. How should a PALS or their CALS handle these invites? Well, if you want to go, by all means, go. Here are a few hints to help everyone enjoy the backyard festivities this summer.

First, call ahead and see what is being served. If there are dietary considerations to observe, offer to bring a dish or 2 that the patient can eat safely, and that others might want to taste and enjoy. How about a Humus with a soft bread (the crust can easily be removed for the PALS) for an appetizer? Why not try a cold gazpacho soup with a mild summer chilli and maybe some Mac and Cheese for the main course? Who could resist

a chilled plain vanilla yogurt (or pudding) parfait with pureed berries blended in and topped with chocolate syrup and whipped cream? Don't forget the drinks, a nice smoothie, an ice cream shake on a hot day, various nectars or even a pina colada can be a pleasant addition to the party.

Now, you have the food and drinks out of the way, what else? Be sure your host/hostess has a safe place for the PALS to get on and off the deck or patio, and a shady area so the PALS is comfortable. Check your surroundings and plan an out if the weather should change suddenly. Be sure any equipment can be accommodated, like outlets for respiratory or communication devices and wheelchairs or walkers will have

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The NY Chapter has a Lending Library available to all PALS.
We have DVDs of movies & TV shows and books on CD or audio tape to lend.
Please contact Christine Dunn at the Chapter office or e/mail dunn@als-ny.org.





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enough room for movement.

How about those personal needs, does the host have toileting facilities that would be easily accessed by the PALS and would it accommodate the caregiver, if needed? Prepare for this, as you would a long car ride – you might want to mind your intake.

Discuss the timetable between CALS and PALS so that neither one of you “spoils” the other’s good time. Don’t hesitate to meet up with friends and family this summer or anytime. Enjoy the sights and sounds and smells and tastes of the next gathering.

Below are a couple of recipes from the High Calorie and Easy to Chew Cookbook that we share with PALS at the Stony Brook ALS center.

Quick Chili - Yield: 4 Servings

Ingredients:

- 1 lb ground beef
- 1 medium onion, chopped
- 2, 14.5 oz cans diced tomatoes (drained)
- 1, 10.75 oz can condensed tomato soup
- 1 tsp salt
- ½ tsp pepper
- 1, 15.5 oz can light red kidney beans (undrained)

Directions:

1. Brown ground beef and onion, drain fat.
2. Add tomatoes, tomato soup, and seasonings.
3. Simmer, uncovered, for 20 minutes.
4. Add kidney beans & simmer for an additional 10 min.

Veggie Mac & Cheese

Yield: 6 servings

Ingredients:

- Vegetable cooking spray
- 12 ounces dry elbow macaroni (about 3 cups dried)
- 1/2 cup white wine
- 4 red bell peppers, stemmed and seeded, cut into small pieces
- 2 medium Vidalia onions, finely chopped
- 3 cloves garlic, finely chopped
- 1 tbsp kosher salt, plus more to taste
- 1 tbsp unsalted butter
- 2 tbsp all-purpose flour
- 2 tsp dry mustard
- 1 cup whole milk
- Freshly ground black pepper
- 1/4 tsp dried oregano leaves
- 16 ounces ricotta cheese

1/4 cup grated Parmesan
bread crumbs for topping

Directions:

1. Preheat the oven to 325 degrees F.
2. Spray a 2 quart baking dish with vegetable cooking spray, set aside.
3. Bring a large pot of salted water to a boil and cook the macaroni until tender, about 8-10 minutes. Drain, rinse under cold running water, and return to the pot.
4. Meanwhile, heat the wine in a large nonstick skillet over medium-high heat. Add the bell peppers, onions, and garlic, and 2 teaspoons of salt, and cook until tender, 10 to 12 minutes, adding a little water if more liquid is needed. Drain the vegetables in a large colander set over a bowl. Add the vegetables to the pasta and set

the juices from the vegetables aside.

5. Melt the butter in a small saucepan over medium heat. Add the flour and mustard and cook, stirring constantly, for 2 to 3 minutes.
6. Whisking constantly, slowly pour in the milk and the juices from the vegetables. Add the oregano and the remaining 1 teaspoon of salt. Cook and stir for 4 to 5 minutes. Season with salt and pepper to taste.
7. Beat the ricotta until smooth and slowly beat in the white sauce. Toss with the macaroni mixture.
8. Transfer to the 2-quart baking dish and sprinkle with Parmesan. Sprinkle bread crumbs over the top and lightly spray them with the vegetable cooking spray.
9. Bake until top is golden brown, about 35 minutes. Serve immediately.