SBAGNE news

Spring 2012 The Newsletter of the Spina Bifida Association of Greater New England

sbaMass

41 YEARS

1971-2012

Notes from the Chair

by Matt Neal

See What I Did There?

I changed the title of this piece, formerly 'The President's Letter'. Now it's less formal, more amusing (to me), and – surprisingly – technically correct. As part of a new formalization of the relationship between the national Spina Bifida Association and the local chapters that's been going on for the last couple of years, we've standardized some of our language. What were once 'Chapters' are now 'Affiliates' and the President of the Board is now the Board Chair. So now I'm a chair, that's all right, I've been called worse.

How'd It Go?

So it's been a busy couple of months since our last newsletter. The most noteworthy happenings being the BLIN'G and BEST weekends. This was our 2nd annual BLIN'G and our 1st annual BEST, and we couldn't be more pleased with the way these events have grown and matured. Check out what Gracie and Jill Lenz have to say about BLIN'G on page 3. The next newsletter will have a write-up on BEST, complete with more photos and personal anecdotes. If you or yours are in the 11-17 age bracket, we'll do this again next year and we want you!

Coming Up Soon

We are just a few weeks away from another fabulous SBAGNE event – the 3rd annual Walk-N-Roll! Walk-N-Roll is part fundraiser and part community-building social event. Both aspects are absolutely critical pieces of the mosaic of our year of service to the Greater New England Spina Bifida community.

The actual event is just a brilliant way to get people together in support of a common cause and with common experiences to just have fun all day long. There is just something about several groups of friends and family joining together to walk together and celebrate their success in really supporting our association that just creates an incredible positive energy. So I urge you to come out and join us on that day, whether you've formed a team, joined a team or simply want to check it out and enjoy the day. It's happening on Saturday, June 16th at the Massachusetts Hospital School campus in Canton, MA (that's the same place where we had our 2011 Summer Picnic). Check out the article in this newsletter or our website for more details.

On the fundraising side, I'll need to get serious for a moment. SBAGNE works hard all year to do what we do – BLIN'G, BEST, the summer picnic, the New England Regional Spina Bifida Conference, the annual constituent benefit and so much more. Most of this just wouldn't happen without the nearly superhuman efforts of our dedicated staff – Ellen Heffernan-Dugan and Wendy Potts. Every year we spend money, and every year we need to raise enough money to fund a year of spending. We do a number of different things to do that, but there are four major fundraisers each year and each one works in a different way. I'll lay that out in more detail in some future not, but the big point is that Walk-N-Roll income paid for 30% of last year's expenses. The way that the fundraising side of this event works is quite unique for us. It's the only event we do where we ask SBAGNE constituents to form or join a team of walkers and then raise small-ish donations from lots and lots of big-hearted people. Those people being the friends, family, and acquaintances of the walkers.

So when you join in and help out at Walk-N-Roll, you are making a real, important difference.

OK, this is a good place to sign off. Enjoy the rest of the newsletter!

Medical Research Corner

Are Antibiotics Necessary With Catheterization?

by Virginia Briggs, Ph.D.

Common practice for avoiding urinary tract infections (UTI) and preserving kidney health is to take antibiotics on an ongoing basis. The thought is that coupling antibiotics with clean intermittent catheterization (CIC) will keep people with Spina Bifida dry and free of infections. However, there is a price to pay for long-term use of these medications. In the medical community, there has been growing concern about the emergence of bacteria that are resistant to treatment. It is believed that overuse of antibiotics is causing bacteria commonly associated with infections in humans to create new drug-resistant forms. Then, when new infections arise, they can be a lot harder to get rid of. So, many ask the question, "is it really necessary to take antibiotics all the time?". A recent study from the Netherlands addressed this question and had some interesting results.

The study was a randomized control trial that included 176 people with Spina Bifida, which were split into two groups: 88 had catheterization with antibiotics and 88 had catheterization without antibiotics. The average age of the participants was 9 years, and they were about equally males and females. During 18 months of follow-up, all participants in both groups had urine cultures every two weeks.

The results showed that there was a slight increase in the number of UTI's in the group that did not take antibiotics. The study also found that males and those that had lower rates of UTI's before the study were less likely to get UTI's without antibiotics. So, the findings suggest that some people may not need antibiotics along with catheterization.

As with all research, these findings are only the result of one study. Additional research is necessary before the urology community will consider making changes to treatment practices that have proven successful for their Spina Bifida patients. However, some people may consider discussing the topic with their urologists based on these results.

REFERENCE:
"Antibiotic prophylaxis for urinary tract infections in children with Spina Bifida on intermittent catheterization". Zegers B, Uiterwaal C, et al. Journal of Urology, 2011 Dec;186(6):2365-70. Department of Pediatrics, Wilhelmina Children's Hospital, Utrecht, The Netherlands.

Jean Driscoll Award 2012

The SBAGNE Board of Directors is now accepting applications for the Annual Jean Driscoll Award. The SBAGNE offers this $1000 scholarship as a tribute to Jean Driscoll, an eight-time Boston Marathon Champion and adult with Spina Bifida. The scholarship may be used for educational, developmental or assistive programs and needs and will be awarded to an SBAGNE constituent, with Spina Bifida who best demonstrates the character and determination of the scholarship's namesake.

Jean Driscoll, who was born with Spina Bifida and has used a wheelchair since her early teenage years, is an accomplished athlete and speaker known around the world. She has enjoyed a life many people can only dream about experiencing. Jean is an Olympic athlete who has won Silver medals in both the 1992 and 1996 Summer Olympic Games. She is a world record holder in the 10,000 meter track event, 10K and marathon road racing distances. She has won the Boston Marathon eight times and is the only person in Boston's 105 year history to achieve this feat. She even has a street named after her in Champaign, Illinois and a park pavilion named after her in Urbana, Illinois.

For official posting and application, contact Ellen Dugan at **edugan@sbaGreaterNE.org**.

BLIN'G Weekend a Success!

A daughter and mother's perspectives

by Gracie and Jill Lenz

My weekend at BLIN'G was so much fun. At BLIN'G I got to meet new people with Spina Bifida and I became very close with some of the girls. I liked when we got the massages and makeovers. I got to laugh a lot with my new friends. Also the entire weekend was amazing. Thank you so much for the opportunity for me to meet girls with disabilities like me. Hope to see you all next year.

Love,
Gracie Lenz

What can I say but WOW what an experience. BLIN'G weekend in Boston was amazing. I had no idea what to expect and this was our first time so nervous about meeting other people. Gracie and I are quite shy when it comes to meeting new people. I was more anxious for Gracie than myself. She had never been around that many girls with the same issues as herself. I believe she thought she was alone. From the hotel to our room everything was thought of. We enjoyed the meet and greet the first night as it broke the ice. The next day was planned out for the girls which by the way Gracie loved. I enjoyed sitting and speaking with the parents. We are networking now as to who can help who with what information. Very helpful indeed. As for the last day we all walked over to MOOO for a lovely lunch and the girls and parents all said their goodbyes. I would highly suggest if you get the chance to participate with your child next year please do. I am in awe of my daughter and the strength she has.

Jill Lenz

2012 BLIN'G Participants

Make plans now to join SBAGNE at its Annual Walk-N-Roll for Spina Bifida!

Saturday, June 16th at the Mass Hospital School in Canton, MA!

WALK-N-ROLL for Spina Bifida

The Walk-N-Roll for Spina Bifida is a family-friendly, walk event being held to raise awareness about Spina Bifida and celebrate the accomplishments of the over 166,000 Americans living with SB. All proceeds are used for programs and services for people living with Spina Bifida. Visit **www.walknrollsbagreaterne.org** for more information!

Interested in partcipating as a walker, team captain or planning committee volunteer? Contact Wendy Potts at **wpotts@SBAGreaterNE.org**.

ARE YOU OR SOMEONE YOU KNOW PASSIONATE ABOUT SBAGNE?

DO YOU OR THEY HAVE SKILLS THAT WILL HELP US FURTHER THE MISSION?

SBAGNE is currently seeking individuals who may have an interest in serving on the SBAGNE Board of Directors. Specific needs include individuals with skills in the areas of marketing, finances, development, event planning. Do you have other talents that will assist in furthering the mission, let us know.

If you are interested in receiving the Board Recruitment Prospectus, contact Ellen at **edugan@SBAGreaterNE.org.**

new balance FALMOUTH ROAD RACE

Team SBAGNE will once again participate in the 40th running of the **New Balance Falmouth Road Race on Sunday, August 12, 2012**.

The race's Numbers for Non-Profits program has given SBAGNE 25 charity numbers.

In 2011, our dedicated Team raised over $35,000 for SBAGNE!
We hope to reach $40,000 in 2012.

Interested in running for Team SBAGNE?
Contact Wendy Potts at **wpotts@SBAGreaterNE.org**

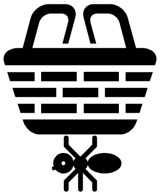
SBA of Greater New England Summer Picnic

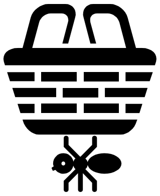
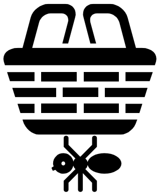
Sunday, July 8, 2012

12pm - 4:30pm

Massachusetts Hospital School, 3 Randolph St. Canton, MA

- **Bring your bathing suits:** swimming in the indoor wheelchair accessible pool with Life guards on duty
- **Wheelchair Accessible Pontoon Boats**
- **Food and Beverages**: Lunch will be provided.
- **Please bring** sunscreen and a lawn chair (if you prefer to the grass or picnic tables!).
- **Picnic Fun:** Activities and surprises for all ages
- **Covered and accessible pavilion with picnic tables**
- **Accessible restrooms**
- **RSVP:** For planning purposes please let us know how many people you expect to bring with you by **July 6, 2011**. RSVP to Ellen Heffernan-Dugan at **edugan@SBAGreaterNE.org** or to the SBA Greater NE Voice Mail (888)-479-1900. If your plans change last minute and you did not RSVP, please join us anyway!




Directions

From Boston: Take the Southeast Expressway to Rte. 128 N. Follow Rte. 128 N. to Exit 2A (Stoughton/Rte. 138). Follow Rte. 138 to second set of lights. Take a right turn onto Randolph St. MHS is about one half mile on the left side.

From Fall River: Take Rte. 24 to Exit 19B (Stoughton). At Sixth traffic light (Rte. 138), turn right. Follow Rte. 138 about four miles. At third set of lights (Randolph St.), turn left. MHS is about one half mile on left.

From New Bedford: Take Rte. 140 to Rte. 24. Follow directions as from Fall River.

From Cape Cod: Crossing the Sagamore Bridge: Take Rte. 6 to Rte. 3 N. to Rte. 128 N. to Exit 2A (Stoughton/Rte. 138). Follow Rte. 138 to second set of lights. Go right onto Randolph St. MHS is about one half mile on the left.

Crossing the Bourne Bridge: Take Rte. 495 to Rte. 24 N. Follow directions as from Fall River.

From Route 95(points North): Take Rte. 128 S. to Exit 2A (Stoughton/Rte. 138). Follow Rte. 138 to second set of lights. Go right onto Randolph St. MHS is about one half file on the left side.

Build Your Own Beach Wheelchair

by Jon Varteresian

A quick look around the web and you will realize just how expensive Beach Wheelchairs can be. Thanks to the the SBA and a small amount of my own money we built our own, and you can too!

First, I poked around the web collecting pictures of commercially available chairs. I used these as templates to build ours. My daughter Katie is around 100 pounds so the chair is built from 1” PVC pipe. If the person you are building for is heavier than that you should increase that size to 1 1/2”. There are a few PVC joints (or fittings) that you just can’t get at the home superstores, but you can them get from PVC furniture stores on the web. I used **www.pvcfittingsdirect.com** for all the unusual parts. You may notice that some pieces are shaped into curves. You can do this by using a standard plumbing torch (outside, of course) and heating the pipe for a few minutes. It will get as flexible as wet spaghetti if you keep heating. Form the desired shape and let cool. Always keep the torch moving or you will burn the surface. Bending of the pieces is not required, however I thought it made the chair look less homemade. Painting is optional.

The wheels are from **www.wheeleez.com** and are by far the most expensive part of the project. I used my yearly benefit from SBA to cover their cost. I used the 49cm size on the front and 30cm on the back. The axle is a 36” long 1” diameter solid aluminum axle with a pin retainer on each end to hold the wheels on. I bought the rear wheels with the caster attachment to make assembly easier.

I wanted the chair to come apart for easy transport so I didn’t glue all the sections together. Instead, I drilled them and used a plastic knob and bolt to hold the sections together. All of the mechanical parts can be found at **www.mcmaster.com**.

The seat is made from 1 1/2” nylon webbing with quick release buckles sewn to pieces of canvas. If you don’t want to sew you can just make a grid of webbing on the frame of the chair (with the buckles) and add a cushion from a patio chair.

Here is what my daughter thinks:

“The best thing about my new beach wheelchair is that it is really easy to get around on the beach. I get to sit comfortably in a huge chair as someone pushes me. Another awesome thing about my new beach wheelchair is that we don’t have to borrow one from the town. Now I have my own PINK ONE! I am so happy to have my new beach wheelchair!”

Feel free to ask me questions at **jonvarteresian@gmail.com**.

SBAGNE Resources

SBAGNE is a great place to find a lot of resources for people with Spina Bifida. The resources are in a binder and include information on camps and recreation, activities and medical information. Additional resources for the Spina Bifida Community can be forwarded to Ellen.

If you are interested in getting some of this information please feel free to call Ellen at 888-479-1900. You can also e-mail her at **edugan@SBAGreaterNE.org**.

Thanks to Katie Jablonski for designing the logo for BEST! Katie is a high school student who enjoys graphic arts.

Beach Wheelchair Construction

A. Parts for the wheelchair

B. Assembled wheelchair with umbrella attached

C. Assembled wheelchair without umbrella

SB National Conference
June 28 - July 1st in Indianapolis

This year's National Conference will feature findings from the Second World Congress on Spina Bifida Research and Care, SBA's international meeting of Spina Bifida health care providers and researchers. Be the first to hear about the latest in care treatment and what is on the horizon for this challenging condition!

Attend educational sessions covering the latest information on Spina Bifida health care approaches including bladder management, weight management, adult-specific health concerns, independence, tethered cord, and accessibility. Kids can enjoy the only national camp designed for children with Spina Bifida and their siBLIN'Gs. Adults with Spina Bifida can participate in an "adult-only" day dedicated to issues challenging this population. During the day, attendees can visit exhibitors' booths filled with the latest products and innovations designed to ease the challenges of life with Spina Bifida.

These are just some of the many reasons the 39th National Conference is a "can't miss." Scheduled from June 28-July 1 in Indianapolis, Indiana, the Conference is an unforgettable experience of learning, sharing, and fun. Each year, the locale, sessions, theme, and even the attendees may vary, but the Conference always retains certain essential qualities: friendliness, discovery, warmth, knowledge, and most of all, support.

For more information or to register for the 39th National Conference, please visit **www.spinabifidaconference.org**.

SAVE THE DATE

Saturday, September 22, 2012

8:30 AM - 4:30 PM

New England Spina Bifida Conference

Sturbridge Host Hotel and Conference Center
Sturbridge, MA

Education Fact Sheets Available Online

SBA has recently published three new Education Fact Sheets on reading, math, and a quick reference sheet for educators of individuals with Spina Bifida. They are now available on the SBA website. Visit the link below, and then click on the Education sheets.

www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2642343/k.8D2D/Fact_Sheets.htm

SB Tween2Teen

A new place for Tweens and Teens living with Spina Bifida. Blogs, videos, Ask the Expert, real stories and Fact Sheets. Visit **www.sbaa.org** and click on the SB Tweens2Teens Logo.

Folic acid, a water-soluble B vitamin, helps your body to build healthy cells. Studies have shown that for women of childbearing age, taking 400 micrograms of folic acid every day can reduce the risk of having a birth affected by a Neural Tube Defect, such as Spina Bifida, by up to 70% .

Orange-Grapefruit Fizz

Ingredients:

3/4 cup frozen Florida orange juice concentrate, thawed

3/4 cup frozen Florida grapefruit juice concentrate, thawed

1 1-liter bottle carbonated water or tonic water, chilled

Ice cubes

Directions:

Pour thawed concentrates into a pitcher. Gently stir in chilled carbonated or tonic water. Pour over ice in glasses. Serve at once.

Makes about 7 (6 oz.) servings

Nutrition facts per serving: 74 calories, 1 g protein, 18 g carbohydrate, 0 g total fat (0 g saturated fat), 0 mg cholesterol, 0 g dietary fiber, 32 mg sodium. Daily Value: 104% vitamin C, 10% thiamin, 14% potassium, 41 micrograms folic acid

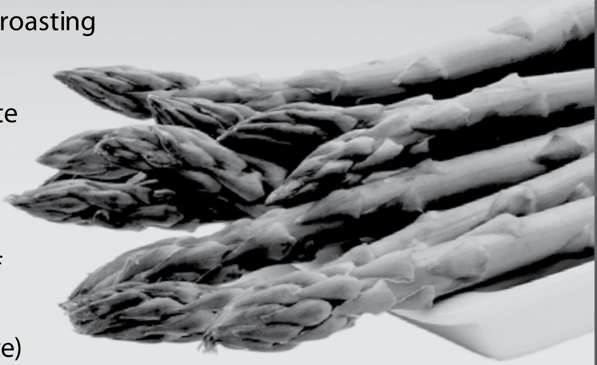
Reprinted permission of the Florida Folic Acid Coalition.

Folic acid, a water-soluble B vitamin, helps your body to build healthy cells. Studies have shown that for women of childbearing age, taking 400 micrograms of folic acid every day can reduce the risk of having a birth affected by a Neural Tube Defect, such as Spina Bifida, by up to 70%.

Roasted Asparagus with Creamy Tahini-Peanut Dipping Sauce

Ingredients:

1 lb. asparagus, thick spears preferred for roasting
1 T olive oil
Sea salt and fresh ground black pepper to taste



Sauce:

(Recipe makes enough sauce for several pounds of asparagus, but have fun thinking of other things it would taste great with.)

1/4 cup well-stirred Tahini (sesame seed paste)
1/4 cup warm water
2 T fresh squeezed lemon juice
2 tsp. agave nectar, preferably amber (can also use sugar or Splenda)
1/2 tsp. ground garlic puree from a jar (or use fresh garlic and grind in mortar and pestle)
2 tsp. soy sauce (I use Tamari)
2 T peanut butter (I use natural low-sugar peanut butter for South Beach Diet)

Directions:

Preheat oven to 425 F. Lightly spray a roasting pan with olive oil or non-stick spray. Be sure asparagus is washed, then cut off the lower woody ends (usually only a few inches, snap one to see.) Cut asparagus into diagonal-sliced pieces about 2 inches long.

Put asparagus in plastic bowl and toss with olive oil, salt, and pepper. Arrange in single layer on baking sheet and roast, turning once or twice, until asparagus is starting to slightly shrivel and brown and is still a little crisp in the center, about 15 minutes.

While asparagus roasts, combine tahini, warm water, lemon juice, agave nectar, garlic, soy sauce, and peanut butter in food processor, blender, or bowl attachment of an immersion blender. (If you use an immersion blender or blender, hold the lid down very tightly! I learned this the hard way.) Blend until ingredients are well combined.

Serve asparagus hot with sauce on the side for each person to dip asparagus into.

(Makes 3-4 servings. Sauce recipe adapted slightly from Chicken and Quickly Roasted Asparagus with Tahini Sauce which was adapted from Epicurious.com.)

Recipe reprinted permission of Kalyn’s Kitchen http://kalynskitchen.blogspot.com.

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Editor: Peter Jablonski

Note: The information in this newsletter is provided solely for informational purposes. It is not intended to be, nor is it, medical advice on the management or care of a person with Spina Bifida. Although every effort is made to assure that information is accurate and current, knowledge in the field of Spina Bifida is growing rapidly and all data are subject to change without notice. Neither the SBA of Greater New England nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The SBAGNE does not endorse any specific medical regimen. You should not change your medical schedule or activities based on the information provided in this publication. Always consult with a doctor, health care provider, or other medical professional before making any medical decisions. The SBAGNE does not employ medical personnel in its organization.

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