



## Notes from the Chair

by Barbara Lee

Hello Constituents and Happy New Year!

As we ring in the New Year I would like to introduce myself and welcome new Board Members to the SBAGNE Chapter! I am **Barbara Lee**. I have been involved in the Chapter for the last 3 years and excited to be serving as the Chair of the Board. As I moved up so did **Rebecca Sherlock**, Vice-Chair of the Board, **Linda Long-Bellil** is now Treasurer and a new member to the Board, **Ginny Briggs** is Clerk. There are other new members who have been appointed to the Board; **Ashley Robinson**, **Kristen Gagnon**, **Stefan Gagnon** (unrelated!), and **Jan Terlaje**. As we continue to grow we are very excited to have these additional members bring great energy, skills and be willing to contribute to our mission!

This will be a great year ahead with new projects and plans in the works! **Ellen Heffernan**, Executive Director and **Thushy Muruges**, Operations Associate have been working hard to expand outreach in Maine and New Hampshire. Therefore increasing our 2014 **Walk-n-Rolls** to include New Hampshire next year! We are hearing about some very interesting fund raisers that will be taking place in the Western MA area which we will be excited to share with everyone as we get more information, so be on the lookout!

Once again, we will be sponsoring **BEST** and **BLING**, activities for families and adults such as the **Summer Picnic**, **Get Active**, and the **New England Spina Bifida Conference**.

We want to thank you for your continued support and participation, without all of you, your friends and families we would not be able to provide the additional programs and services. Please give us your suggestions and feedback along the way so we can continue to get better and better!

Thank you, sincerely,  
Barbara Lee, Chair

### SBA National Conference June 29 - July 2nd 2014 Anaheim CA Mark Your Calendars Now!

Through exceptional medical sessions, practical workshops, and memorable social events, the SBA National Conference is an exciting and informative event that has truly earned its place as the world's premier conference serving the spina bifida community.

Held during the end of June each year, the Conference is one of our community's most loved events. It features not only the education sessions but is also home to SBA's Kids!Camp, the only national camp for children living with spina bifida.

Watch [SBAGreaterNE.org](http://SBAGreaterNE.org) and this newsletter for information regarding stipends to attend the National Conference.

## Thank You!

The patrons of **T-Stop Variety, Lynn Mass.** Their generous continued support provides significant assistance to Spina Bifida Association of Greater New England (SBAGNE). Funds raised each year allow SBAGNE to make available the Illuminations Program for SBAGNE constituents. The Illuminations Program incorporates age appropriate mailings to families and adults as they "age up" at significant stages in their lives. This important information permits individuals to prepare for changing needs, both medical and social.



### BLIN'G (Better Living N' Girls) Weekend

**February 28 - March 2, 2014**  
in collaboration with Children's Hospital-Boston

BLIN'G weekend is for girls ages 12-17, living with Spina Bifida and a parent. The weekend consists of education,

social and recreational activities.

Two nights in an area hotel, meals and activities are included.

Cost is \$25 per family.

For more information, please visit  
[SBAGreaterNE.org](http://SBAGreaterNE.org)

### Annual Benefits Program

Visit [SBAGreaterNE.org](http://SBAGreaterNE.org) for more information and an application. Apply today!



**Join SBAGNE on June 7th, 2014**

**4 Locations in 2014 !!!!**

**Canton and Westfield Mass  
Scarborough ME  
Manchester NH**

SBAGNE programs and services are supported by generous individual donors, matching gifts, grants and fundraising events.

Join us to raise awareness and funds in support of the Spina Bifida Community.

To be a sponsor, support a team, start a team or volunteer

Log onto

[www.walknrollsbagreaterne.org](http://www.walknrollsbagreaterne.org)

or contact

Thushy

[tmuruges@SBAGreaterNE.org](mailto:tmuruges@SBAGreaterNE.org)



### Jean Driscoll "Dream Big" Award

The SBAGNE offers this \$1000 award as a tribute to Jean Driscoll, an eight-time Boston Marathon Champion and adult living with Spina Bifida. The SBAGNE is seeking to support an individual in "pursuing their passion" as Jean Driscoll has in her life. The award may be used for educational, developmental or assistive programs and needs and will be

awarded to a SBAGNE constituent of over the age of 14, with Spina Bifida who best demonstrates the character and determination of the scholarship's namesake. An individual can self-nominate or be nominated by another. If you're interested in applying, download the Application form from [SBAGreaterNE.org](http://SBAGreaterNE.org).



### **BEST** **(Boys Esteem Success Training)** **Weekend**

**April 25-27, 2014**

in collaboration with Children's Hospital-Boston

BEST weekend is for boys ages 12-17, living with Spina Bifida and a parent. The weekend consists of education, social and recreational activities.

Two nights in an area hotel, meals and activities are included.

Cost is \$25 per family.

For more information, please visit

[SBAGreaterNE.org](http://SBAGreaterNE.org)

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%.

### **Best Banana Bread Recipe**

#### **Ingredients:**

- 2 cups all-purpose flour
- 1/2 cup sugar
- 3/4 teaspoon baking soda
- 1/2 teaspoon salt
- 1 cup toasted walnuts or pecans chopped
- 3 ripe, soft, darkly speckled large bananas, mashed well (about 1 1/2 cups)
- 1/4 cup plain yogurt
- 2 large eggs, beaten lightly
- 6 tablespoons butter, melted then cooled
- 1 teaspoon vanilla extract

#### **Directions:**

Adjust oven rack to lower middle position and heat oven to 350 degrees. Grease bottom only of regular loaf pan, or grease and flour bottom and sides of nonstick 9-by-5-by-3-inch loaf pan. Combine dry ingredients together in large bowl and set aside. Mix mashed bananas, yogurt, eggs, butter, and vanilla with wooden spoon in medium bowl. Lightly fold banana mixture into dry ingredients with rubber spatula until just combined and batter looks thick and chunky. Pour batter into prepared loaf pan; bake until loaf is golden brown and toothpick inserted in center comes out clean, about 55 minutes. Cool in pan for 5 minutes, then transfer to wire rack. Wrap tightly with plastic wrap and store in refrigerator for 4 days, on the counter for 2 days.

Recipe from Arkansas Folic Acid Coalition





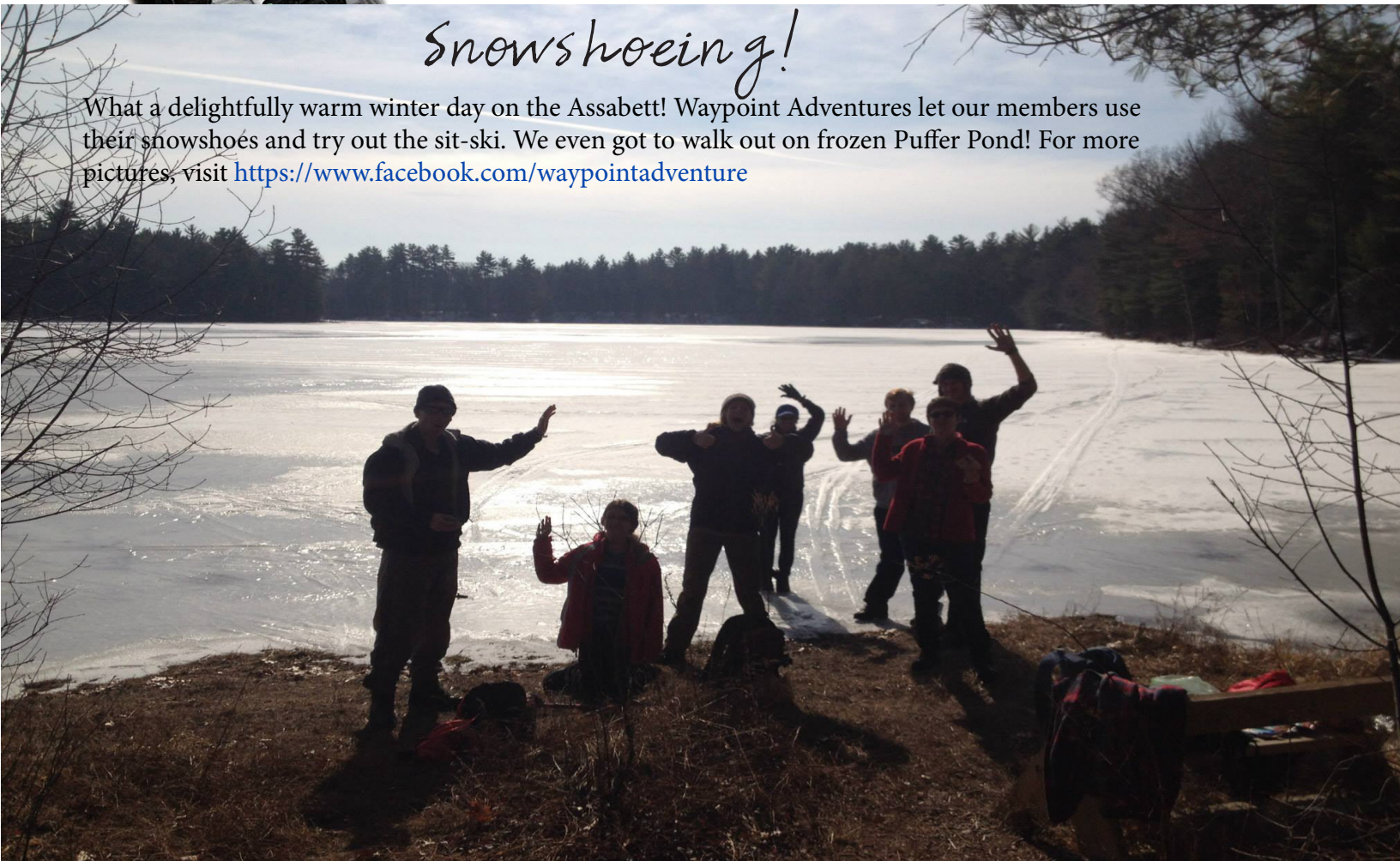


## *Holiday Parties!*

This year there were three (yes, three!) Holiday Parties! All were visited by the jolly old elf himself where he visited with all the good little girls and boys (and some not so little girls and boys!). For more photos of the good times, visit [SBAGreaterNE.org](http://SBAGreaterNE.org).

## *Snowshoeing!*

What a delightfully warm winter day on the Assabetts! Waypoint Adventures let our members use their snowshoes and try out the sit-ski. We even got to walk out on frozen Puffer Pond! For more pictures, visit <https://www.facebook.com/waypointadventure>





## Paralyzed swimmer inspires other disabled kids to chase dreams

by FELIPE JOSIAH RAMOS

MANILA, Philippines - Through her example, Calistha Jillianne R. Salazar encourages every child with disability to pursue their dreams of being an athlete despite the long odds they face.

Despite being born with Spina bifida, Salazar, 9, conveyed no hesitation as she descended from her small wheelchair to swim at the Rizal Memorial Pool in Manila in front of a large audience. Her poise betrayed no signs of a lack of confidence in her abilities.

"We are very happy to see her swim in front of many people and we're so thankful to God for the blessings he gave our daughter," Jillianne's father Elvin, who currently works as a Seaman, tells Rappler.com.

"We raised her like a normal child with confidence. The good thing is she's very smart and diligent, so that's why raising her isn't hard for us. She really wanted to be a model for every disabled child. She's not bothered by her disability. She is very positive," he added.

Spina bifida is a condition of the lower spinal cord that causes paralysis of the legs from birth. It is considered one of the most common birth defects with a worldwide incidence of about one in every 1000.

Two weeks ago, Jilliane stole the limelight from the other competitors in the 52nd Philippine Swimming League Leg Series' The Manila Times College (TMTTC) Swimming Championship.

She swam in the 50-meter breaststroke event and finished with a best time of 2:21.13 to capture the gold medal and received P5,000 in cash incentives from PSL legal adviser Atty. Luz Arzaga-Mendoza.

"She can't walk ever since but she inspires everyone not to lose hope and pursue every dream they have," said PSL President Susan Papa during the annual swimming event that attracted 500 participants from 61 clubs all over the country.

Jillianne was accompanied by her father, mother Elma Salazar and 12-year-old brother Lance during the special event of the competition.

If her plans push through, Jilliane could become a member of the country's paralympic team in the future.

"There is no plan yet if she can join the swimming 'para' games team because she's still very young and this is the second time she [has] competed in a swimming tournament," added by Jilliane's father. "We are just hoping she develops well in swimming despite her situation.

"But who knows? If that's God's will, then so be it. We are so thankful to the PSL for giving our daughter a chance to swim in their tournament."

Jillianne, a third grader who studies at Governor Hills Science School in General Trias Cavite, began swimming last June 2013 for her therapy, but swimming instructor Junnet Abesamis advised her parents to allow their daughter to join competitions.

"I told her (Jilliane) parents why not allow her to swim in different competitions? That will be a good exposure to her to build up her confidence," said Abesamis in a separate interview. "She is also a member of the Department of Education team in Cavite."

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# OUTREACH

## FAQs about spina bifida

[www.spinabifidaassociation.org/site/c.evKRI7OXIoJ8H/b.8095307/k.4C3B/FAQs\\_About\\_Spina\\_Bifida.htm#.UvqHjiPTl84.email](http://www.spinabifidaassociation.org/site/c.evKRI7OXIoJ8H/b.8095307/k.4C3B/FAQs_About_Spina_Bifida.htm#.UvqHjiPTl84.email)

## Adaptive and Inclusive Outdoor Fun

### *Massachusetts*

State Parks Across Massachusetts, DCR's Universal Access Program  
[www.mass.gov/eea/agencies/dcr/massparks/accessibility](http://www.mass.gov/eea/agencies/dcr/massparks/accessibility)

### *Maine*

Get Active with Maine Adaptive! Year round programs for individuals with various disabilities.

[www.maineadaptive.org](http://www.maineadaptive.org)

### *New Hampshire*

[www.NH.gov/disability/information/community/recreation.htm](http://www.NH.gov/disability/information/community/recreation.htm)

### *Vermont*

[www.vermontadaptive.org](http://www.vermontadaptive.org)



Team Spina Bifida is the Spina Bifida Association's athletic program for spina bifida supporters across the country. Friends of SBA train for and complete a marathon, half-marathon, or other endurance event (triathlon, cycling, mountain biking, etc.) or participate in a team sporting event. Team Spina Bifida seeks to RAISE FUNDS and AWARENESS for spina bifida.

On March 9th Dr. Carlos Estrada and Stephanie Fenner are participating in the LA Marathon as part of TEAM SBA. Funds raised by Dr. Estrada and Stephanie will support SBAGNE programs and services in 2014.

Visit [www.SBAGreaterNE.org](http://www.SBAGreaterNE.org) to show your support for their efforts on behalf of SBAGNE.

## **Contacts**

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