

SBAGNE

news

Spring 2013

The Newsletter of the Spina Bifida Association of Greater New England

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Notes from the Chair

by Matt Neal

It's mid-May and lots of people are waiting as patiently as humanly possible for me to deliver these notes to the newsletter so that the newsletter can be delivered to you. It's a recurring drama, happens every three months or so. I say this more for the amusement of the aforementioned lots of people than to make any particular point. Suffice it to say that I am late again and here's what's on my mind today.

Mid-May... just a few weeks since mid-April. The bizarre, brutal, and unsettling Boston Marathon bombing sent us all reeling into unfamiliar territory. We got through it though; we've come out the other side. Changed forever no doubt, but through it. As Americans, New Englanders, Bostonians; we got through it by going through it together. Reaching out for help and reaching out to help. The courage, composure, and action of the people in the medical tent, the first responders, and so many others who suddenly found themselves in the middle of it all were just inspiring. So we all pitched in as we were able to help those most affected get their lives back on track, and of course the story goes on.

This notion of gaining strength from each other by being there for each other is where I make a connection to our little group here. Our mission statement says, in part, that we are here to enhance the lives of all affected by Spina Bifida. Sounds innocuous, but consider what that means to each of us personally. I know we can all call up moments where the immediate future was starkly formidable. What's the right decision? How to adjust to a new reality? How to navigate through the unknown? It helps a lot to know people who are going through it too, it helps a lot to have good information, and it helps a lot to just have fun. That's what we do and that's why we're here.

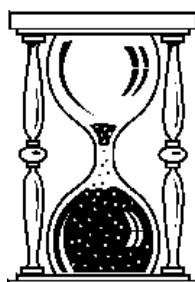
Thanks for reading, and I hope you enjoy the rest of our newsletter!

SBAGNE

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YEARS

1971-2013



**Time's
running
out!
Register
now!**



for Spina Bifida

Presented By



Visit
walknrollSBAGreaterNE.org
today!



Presented By



**Three locations
this year!**

***There's still time to register to
Walk-N-Roll!***

Make plans now to join the Spina Bifida Association of Greater New England at its 4th Annual Walk-N-Roll for Spina Bifida® on **Saturday, June 15** at **Massachusetts Hospital School in Canton, MA, Stanley Park in Westfield, MA and Rock Church, Scarborough, ME**. You pick the location that works best for you!

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 it. All proceeds are used for programs and services for people living with Spina Bifida. Visit **www.walknrollsbagreaterne.org** for more information!

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



Team SBAGNE will once again participate in the 40th running of the
New Balance Falmouth Road Race
on Sunday, August 11, 2013.

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

In 2012, our dedicated Team raised over \$35,000 for SBAGNE!
We hope to reach \$45,000 in 2013.

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

***Thank you
for your support of
BEST and BLING!***

CVS | DCU 
CAREMARK For Kids
**EILEEN
FISHER**

WE HAVE A WINNER!

The winner of our
Walk-N-Roll early registration contest
for a Target Gift Card is
BRENDA RAIA
of Team Colton's Crusaiders!
Way to go Brenda!



SAVE THE DATE

**Saturday,
September 21, 2013**

8:30 AM - 4:30 PM

**New England Spina Bifida
Conference
Sturbridge Host Hotel and Con-
ference Center
Sturbridge, MA**

**Visit SBAGreaterNE.org
for more details**

BLIN'G Weekend a Success!

A daughter and mother's perspectives by Abigail & Elaine Bemis

I had an amazing time at BLING. I particularly enjoyed the Reiki, Adaptive Sports and lunch at Margarita's. The Reiki really helped me relax, the Adaptive Sports made me want to participate in sports and the lunch was delicious. I really enjoyed the churros (fried cinnamon sticks)! Although the pool was closed, we watched an awesome movie and had ice cream instead. I hope I am able to go next year.



Abigail

Just when you thought BLING could not get any better, it did. The weekend started off with a bang with group activities and a visit from Ms. Wheelchair Massachusetts who helped the girls write their own song. The new location at the Newton Marriot provided different opportunities for the girls and parents. The venue allowed the girls to try out adaptive sports equipment and the parents to see options in van modifications. The presenters and guests were great role models for us all. I enjoy being able to connect with other parents and share experiences and suggestions. The thing I like best about the weekend is watching the girls meet up with old friends and make new ones. Thanks to all who made this amazing weekend possible!

Elaine







Great Weekend for BEST!

by Jeremy and Vanessa Evans

A son and mother's perspectives

The BEST weekend was definitely successful and it seemed to be a great time for everyone. Personally I enjoyed it because it gave us a chance to connect with people who share similar experiences in our lives which makes it feel better to have people around that actually understand. I made new friends. The hotel we stayed in was very nice and the activities and discussions that we had were also great. The one thing that was leaning towards the bad side was having too many sandwiches for our meals. Other than that, it was an excellent weekend and I would do it again. Thank you.

Jeremy

I love the BEST weekend. It's great to watch Jeremy interact with other boys with similar issues. He came away from the weekend with a different outlook on his disability. I also enjoy talking with other parents and share our experiences concerning our children, whether it be medical or social, and it's good to hear different ideas on how to cope with both. Parents with younger kids also see that "it's not so bad" after all when they see and talk to kids and their parents who have more years and experience behind them. The activities were fun, but I think I'd like to see more outdoor if the weather permits. The hotel is awesome and the staff there were very accomodating to us. Food was good...most didn't want too many sandwiches...but I thought it was fine. Maybe next year, we can have a spaghetti night that we can prepare ourselves in one of the suites with a salad. I think the kids would like that. The two nights was better, it gave us more time and we didn't feel rushed. I would definitely do it again. Thanks SBAGNE!

Vanessa





Adaptive Skiing a Big Hit Even During the February Blizzard!

by Katie Packard

This year I tried skiing for the first time. I was really scared at first because I don't have good balance at all. I thought that it was a good idea because I had been watching my brothers and dad ski for many years. They looked like they having so much fun so I decided to try it. I went to Bretton Woods, in New Hampshire, to learn. Their adaptive program is called New England Disabled Sports. For many years they were based at Loon Mountain, but now have come to Bretton Woods too. It does not matter what kind of disability you have. The people that work with the program make sure that anyone who wants to ski can ski. The instructors that work there have even worked with people with amputations or no legs at all. Because the weather wasn't great, I had four amazing instructors helping me while I skied. I was not sure about skiing at first, but once I tried it I loved it. I really want to go again sometime. The instructor made sure that I was comfortable before I went out on the snow. Before I could start practicing, I had to make sure I had the right size boot. When I went skiing I had a two hour lesson. Out of the time that I had I used about 45 minutes to make sure that I had the right size. I had to try on a few different sizes before I found the right one. After I found the right size boot I practiced basic steps to skiing on the carpet. Once I was ready to leave the carpet we went out on the snow. Skiing wasn't as hard as I thought it to be, although I did fall at least three times. The hardest part about skiing was that when my family and I went to Bretton Woods it was during the February blizzard. So it was kind of hard to see through the snow. Minus the blizzard, skiing was really fun and I would suggest that anyone that ever thought about trying to ski should do it. I have to say it was one of the most fun things that I did this winter.



Katie Packard shushing down the slopes during the February blizzard.

Nordic Skiing with the Faherty Girls

by Mary Faherty

It was a beautiful March day; a perfect day to go skiing. This was our third attempt to try Nordic skiing this winter; the first time I had to cancel because Catherine was sick with the flu and the second time was canceled due to poor ski conditions.

I took my girls (Catherine, 8, and Fiona, 6) out of school a little early and headed for the Weston Ski Track in Weston, MA. We had never been Nordic skiing before (and the girls had never even been skiing before) and thus we were all a bit nervous.

We arrived at the parking lot and there was plenty of parking. In fact, there were very few cars there. We were instructed to proceed behind the building for the accessible skiing. We were the first skiers there, except for the instructors and volunteers. They all made us feel very welcome and at ease. They fit Catherine to a sit ski and sent me and Fiona into the rental shop to be fit for equipment. All three of us were able to ski free of charge. Not only did they not charge us rental fees for the equipment, they also gave each of us a ski pass for the afternoon.



Fiona (left) and Catherine (right) Faherty glide with ease at the Weston Ski Track.

The afternoon of Nordic skiing was sponsored by Spaulding Adaptive Sports Centers. Patrik Viljanen, the Adaptive Program Manager of New England Nordic Ski Association, was the instructor and provided all the adaptive equipment. There were also a handful of volunteers to help instruct and help wherever needed.

No other participants came to adaptive ski so it was just the three of us. Patrik skied with Catherine and another volunteer skied with Fiona. After brief instructions and a few passes on the flat track, we were ready and eager to try the rolling hills. At first Patrik held Catherine from the back of the bucket, but as she continued on, she was able to do more and more on her own. By the end of our first lesson, Catherine was able to ski independently. However, Patrik was there at all times for assistance whenever needed. He primarily had to assist her up the rolling hills.

The other volunteers were able to take pictures of our first experience skiing as a family. At the end of our session (about 90 minutes or so), one of the volunteers even offered the girls homemade oatmeal raisin cookies. What more could you want!

As Catherine said when we got in our car “Mom, I didn’t like skiing, I loved it”.

Over the next week and a half we went Nordic skiing two more times. We are hooked. What a great family activity that we can ALL do together. And it was all free.

During the winter of 2013 New England Ski Association offered skiing throughout the winter months: one weekday morning session and one weekday afternoon session. Spaulding Adaptive Sports also sponsored a few additional sessions.

The Weston Ski Track is only minutes from Rt. 128 and the Mass Pike and is the property of Department of Conservation and Recreation (DCR). Unfortunately the building is NOT handicap accessible. The bathroom facilities are on the lower level and can only be accessed by stairs. Additionally, the bathroom facilities (stall, toilet and sink) are also not handicap accessible. One more thing to add to my long “To Do List” - contact the DCR to find out why.



SBA of Greater New England Summer Picnic

Saturday, July 13, 2013

12 PM - 4:30 PM

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 8, 2013**. RSVP to Ellen Heffernan-Dugan at edugan@SBAGreaterNE.org or to the SBAGNE 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 mile on the left side.

Piers Park Sailing

The Adaptive Sailing Program at Piers Park Sailing Center is a nationally recognized non-profit sailing program which has served over one thousand people with disabilities since the program's inception in 2007. In 2009, US Sailing awarded PPSC as the Best Community Program for disabled sailors. In 2010, we were honored to be designated a Paralympic Sports Club.

PPSC's program objectives are to empower our sailors with disabilities to realize their recreational goals using adapted teaching methods and a full array of adapted equipment. Our sailors tell us that while learning the important sailing skills, they are rewarded with a sense of confidence while being challenged by the sport of sailing.

Visit piersparksailing.org today to learn more about their programs.

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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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