

June 2014

The Newsletter of the Spina Bifida Association of Greater New England

Notes from the Chair

Barbara Lee

Hello Everyone,

Finally we can welcome the warm weather in and the cold out... right? We have great events planned for the next few months that we hope you can participate in and enjoy.

As you can see on our website we have the upcoming Walk n' Rolls listed, taking place in Massachusetts, Maine and New Hampshire. Please check them out and join in the event in your area and the fun. On June 7th, 3 Walk n' Rolls are taking place! They will be in Canton, MA, Westfield, MA and Scarborough, ME. On June 14th New Hampshire will host theirs in Manchester, NH. Remember that your donations make all that we do for you throughout the year possible.

We are running the Race! We have a team of runners that will be participating in the Falmouth Road Race! We are lucky to be a part of such a great race and we are happy that we have been able to get a team together to help support SBAGNE this year.

On July 19th we will be hosting the Annual Summer Picnic at the Mass Hospital School in Canton, MA. This is a great day where you can go on the boats in the pond,, the swimming pool is open and we have wonderful barbeque food that is cooked by staff of the School. We would love to see everyone who can come enjoy the day, (and we know the weather will be great!) and have fun meeting new families and friends.

At the end of June some of you may be going to California to the National Conference in Anaheim. If we haven't met you before, maybe we will see you there! We are hoping to learn a lot as we always do at this conference but also have the opportunity to network with other chapters and learn from them as well. Those who do have the chance to go always come back happy that they were able to meet new people and meet up with old friends too!

Once again we need to thank everyone at this time, who tirelessly volunteers to assist with these events and make this all happen! So thank you all!

Sincerely,

Barbara Lee

Chair

Jean Driscoll "Dream Big" Awardee Jeremy Evans



For a long time I've wanted to be like my own doctors and pursue a career in the health professions, so that I would have the opportunity to make an impact on people living with disabilities.

I never really knew exactly how I wanted to make an impact, and to be honest, I still don't know exactly how. But I do know that I want to inspire people living with disabilities and to make them feel like they don't have to be ashamed of themselves or have to live by their limitations. I want to make people feel limitless, as I have felt for almost my whole life.

I will be attending UMass Dartmouth in the Fall majoring in Biology, with an ultimate goal of attaining a Master's Degree in Prosthetics and Orthotics. I want to be able to contribute in the development of new and better braces for those who need them.

Get Active with SBAGNE and Waypoint Adventure

SBAGNE is teaming up with Waypoint Adventure for another Get Active initiative. Join us on Saturday- JUNE 28th at 10am for OUTDOOR ROCK CLIMBING.

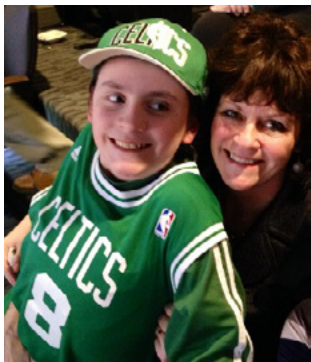
"Waypoint Rock Climbing will provide a safe and comfortable environment that is adapted to fit your needs. During this program you will be encouraged to challenge your limitations and reach your goals while also being introduced to the sport of rock climbing. Waypoint will provide equipment, personal instruction, climb time and trained staff who will support and instruct you as you experience the benefits and freedom that go along with this amazing sport."

Falmouth Road Race 2014

Great News! We have received charity numbers for the 42nd Annual Falmouth Road Race. The numbers are going quickly. The minimum fundraising goal for each runner is \$750. If you are interested in running in FRR as well as raise money for SBAGNE, please contact Thushy at tmuruges@SBAGreaterNE.org.



Sean and Kim Farrell



Sean
“This year’s BEST weekend was my very first time attending. I have to say that I had a fantastic time! One of the reasons that I really loved this event is all of the nice boys that I got to meet. (And hopefully I will be able to invite them to my house one day for a pool party.)

Some of the events were awesome and a couple were not very enjoyable. I didn’t like the boxing because I was not certain what the guy was telling us and I also felt that some of the moves were dangerous for someone who has spina bifida. The other event I didn’t like was the transition planning because it was boring and I didn’t really get anything out of it. But those two things aside, I loved everything else! I loved the weightlifting with Andy and his confidence. It made me feel that I can do it too. I also loved the Adaptive Sports with Megan, Omar and the group. Being able to play softball and basketball with the group was so much fun! Since the BEST weekend, I joined a sports program at the Mass Hospital School and recently found out about wheelchair basketball leagues that are close to where I live. I hope to play in a league one day.

I would tell anyone who has interest in coming to the BEST event to do it! Please come because at the end of the event you will want to come back again and again, like me!”

Kim
“Having been part of the SBAGNE for a while now, this was the first opportunity we had as a family to attend the BEST weekend. I can tell you all, it did not disappoint! From the minute we walked into the Mass Hospital School Rec Center, we knew we were in a very special place with a group of very special people. The warmth we were greeted with along with all of the smiles made us feel right at home. It was wonderful to meet the families who have been part of the BEST event previously as well as the new families like us who were excited to be included.

Sean is a sports fanatic and has been interested in pursuing something along those lines; eventually getting into sports broadcasting knowing him. So for us to experience first-hand the capabilities of the group we met and the possibilities of what he may be able to do were more that we could have hoped. I also enjoyed watching the interaction with the boys as they participated in the educational sections of the event. Their curiosity and interest in the subjects being discussed was great to see. I can tell you that the Bone Health discussion along with strengthening has been woven into Sean’s daily routine!

For me, spending time with the other families and sharing not only related issues but openly discussing things that are either being considered, be it medical or educational, was a tremendous source of insight. As a parent always seeking information about what to expect in the next year or year after has been a complete mystery, so to have a chance to network with other parents, Rebecca and Ellen was more than I could have hoped for at the event. And I would be remiss if I did not give a shout-out to the athletes who volunteered their time to come work with the boys and meet with the parents. My heart was so full of pride when I saw Sean the first time ever play not only softball but also basketball...it really reinforced the old saying that “anything is possible”.

Finally I do want to thank Ellen for inviting us to the BEST weekend but also to Rebecca and Thushy along with Ellen for their thoughtfulness in laying out the agenda, accommodations, food and most of all fun! Thank you for everything! We cannot wait to come next year!!”

SBAGNE Summer Picnic

July 19th, 2014 10:30 – 3:00pm
Massachusetts Hospital School, 3 Randolph St.
Canton, MA

Swimming 10:30-12:00
Lunch and Games 12:00-1:30
Pontoon Boats 1:30-3:00

- 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 (or if you prefer 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 11, 2014**. RSVP to Ellen Heffernan 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!

Annual Constituent Benefit

The Annual Financial Benefit Program applications are currently being accepted. The maximum benefit is \$250 per member with spina bifida. First round application are due **June 30, 2014** by midnight. Please visit our Benefit Page on our website for more information.

Save the Date!

**New England Spina Bifida Conference
Radisson Hotel, Nashua NH
September 13, 2014**



Welcome Pawan!

SBAGNE has a new intern. Pawan Hauljory is a Master’s candidate at Clark University. He comes to the table with years of work experience in his home country, Mauritius and in the U.S. He has a M.S. in Corporate Governance and Corporate Social Responsibility and BSC in Sociology. He is fluent in French, Mauritian Creole and English.

We are excited to have him onboard. Pawan will collaborate with Ellen on grant writing activities for SBAGNE. Make sure to connect with him at our events.



New things are happening!

New Office

SBA is moving. As of Friday, May 16 our new contact information is:

Spina Bifida Association
P.O. Box 17427
Arlington, VA 22216
Toll free: 800.621.3141
Fax: 202.944.3295



New President and Chief Executive Officer

In April the National Office welcomed Sara Struwe as President and Chief Executive Officer. [Read More...](#)



On June 7th SBAGNE held walks in Canton and Westfield Massachusetts and Scarborough Maine. We were fortunate to have perfect weather and a remarkable sense of community.

On June 14th SBAGNE held its first Walk N Roll in Manchester, NH. Funds raised allow SBAGNE to continue to provide programs and services to the Spina Bifida Community throughout the year. We can still use your support, visit www.walknrollsbagreaterne.org.

Watch for pictures and more information in the upcoming newsletter.



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