SB® SBAGNE news

August 2014 The Newsletter of the Spina Bifida Association of Greater New England

Notes from the Chair

Barbara Lee

Hello Everyone,

I hope that you are all enjoying this weather and having some good old fashioned FUN!

As you can see on our website we have completed the Walk n' Rolls and they did great! We hope that everyone who participated enjoyed the fun and meeting new friends and families. Remember that your contributions make all that we do for you throughout the year possible! Thank you!

We hosted 2 summer events. Portland Seadogs on July 14th and the Summer Picnic at the Mass Hospital School in Canton, MA on July 19th. Both events were well attended and attendees are looking forward to summer 2015 events

We were so pleased to see many of you at the National Conference in Anaheim at the end of June! I understand that the medical information was informative and that the Kids Camp was great! Ellen Heffernan and I learned from other chapters on some new ways to provide services. Ellen and Rebecca Sherlock, R.N. were very pleased to be asked to share our program that we provide BLING and BEST with the other chapters and to explain how we manage to do 4 chapters in 2 weeks too!

Summer Picnic Fun!

If you are in Falmouth on August 17th we have a team of runners that will be participating in the Falmouth Road Race. Cheer them on! Go Team SBAGNE!

Saturday, September 13, 2014 is our Annual Conference will be hosted in Nashua, New Hampshire at the Radisson Hotel. We will have an informal reception on Friday evening for those of you who plan on staying overnight. The conference includes excellent breakout sessions, kids camp, and many exhibitors to get the latest information. Please go to our website to get additional information on the conference and to register. Mark your calendars and hope to see you all there!

Once again I would like to thank all of you who tirelessly volunteer your time to make these events possible and go off without a hitch!

Sincerely,

Barbara Lee

Chair SBAGNE

From First-Timers at the National Conference in Anaheim, CA

Rafael Cardenas

A very special and heart-felt thank you to SBAGNE for granting us a scholarship to attend the National Conference in Anaheim, CA this year. It was our first time attending, our first time in California, and well worth the trip! In order to get as much information as we possibly could, we split up the sessions and attended the ones most relevant to our lives right now. We learned more about executive functioning issues, bladder and bowel management, transitioning and self-advocacy, what's new in PT and a little about adaptive exercise, and we talked with other parents who have been through similar situations. We saw friends from Massachusetts, and made new ones from many different states. We were amazed that so many families (and individuals) came from so many states!

Although a little hesitant at first, my children loved Kids Camp, and each made new friends, even friends from different countries! Their first day at Kids Camp, they didn't want to leave! Of course, we also enjoyed the Disneyland Hotel, the pool, the waterslides, Goofy's Kitchen, and DISNEYLAND! For any family that hasn't been to the National Conference, we highly recommend it, it's an amazing, wonderful, educational experience!!

Miss Wheelchair Massachusetts 2014 with Friends and Family

October is Spina Bifida Awareness Month Assist SBAGNE in increasing awareness

Recognize that you are an expert in spina bifida – no one knows better what people with spina bifida need and deserve than you! That means that you have knowledge, understanding, experience, and insight that others do not; they need to hear from you directly so they can know what policies, procedures, situations, or circumstances need to be changed to better meet the needs of people with spina bifida and to help improve quality of life for those affected. You have the power to do this just with your own voice…and we can help!

Submit a letter to the editor of your local newspaper to help educate your community and elected officials about spina bifida. Just as all politics is local, all local politicians and their staff read their local papers and follow their local news, including reading the letters to the editor to keep their fingers on the pulse of the concerns of their constituents. A letter to the editor of your local newspaper on spina bifida will help educate policymakers and your community about the nation's most common permanently disabling birth defect. Letters must be concise and specific and should include a local angle, such as including state statistics on spina bifida. Each local paper has different rules for submission of letters to the editor – typically these guidelines can be found in the front section of the newspaper on the editorial page or on the online version of the newspaper. Also, some papers have different letters sections in print and online.

Visit **www.SBAGreaterNE.org** or follow us on Facebook and Twitter for additional ideas.

Annual New England Spina Bifida Conference

Radisson Hotel
Nashua, NH
September 13, 2014

A Conference For Families, Individuals, Health Care Professsionals and Educators

Plenary Session: Lessons for a Lifetime

Moderator- Brendan Sullivan

Panel of adults living with spina bifida sharing their successes and challenges

Additional Presentations:

- Bullying
- Adult Urology
- Transition to adult medical services
- And more to come

Conference stipend available

for MA, ME, NH and VT residents only of up to $250 per individual or family. Application form at **SBAGreaterNE.org**.

Registration Now Open!

Visit https://registration.sitesolutionsworldwide.com/synergy/v_1_/home/login.php?ccc=9_95_907&syntrack=&scid=907 to register today.

Overnight Room Rate $89 until August 23rd.

Check out **SBAGreaterNE.org** for more information.

Will my child's life be better after this surgery? Quality of life in children with spina bifida.

Konrad M. Szymanski, MD MPH, Rosalia Misseri, MD, Benjamin Whittam, MD, Shelly King, RN CPNP, Martin Kaefer, MD, Richard C. Rink, MD, Mark P. Cain, MD
Division of Pediatric Urology, Riley Hospital for Children at IU Health, Indianapolis, Indiana

Doctors have a perception of what might make children and families happy. But our real desire is to find out how happy children and families really are. We would like to investigate children's feelings further, to see if the care and surgeries we provide are enhancing their quality of life. In order to properly assess a person's quality of life, special questionnaires are necessary. Asking: "Are you feeling better or happier?" is just not enough. Questions for patients need to be understood and answered by the patients and families. The questions need to focus specifically on what is important to the patients. But, this process takes time… and help from patients and their families.

The Division of Pediatric Urology at Riley Hospital for Children is developing a questionnaire for children and teens with spina bifida to allow us to measure the quality of life of our patients. This questionnaire will help us understand if patients are doing better in certain areas of their life, or struggling in others. We want to improve the quality of life of our patients. You can help!

We are looking for children 8-12 years old and teenagers 13-18 years old with spina bifida who had surgery on their spine as a newborn. Ultimately, we hope this will help others with spina bifida. Helping with this important project would require people with Spina Bifida and their parents or caregivers to complete a 20-minute anonymous online questionnaire on a secure website. We do not keep patient information and all information is anonymous. We will ask for a few general medical details, as well as questions about how the child, teen or adult with spina bifida feels.

If you are interested in participating in our project, please go to: **www.surveymonkey.com/s/QSB** to fill out the questionnaire.
We thank you for your help!

Extreme athlete taking wheelchair to new heights

Manual Bojorquez

IRVING, Texas – In the world of extreme sports, there is no one like 22-year-old Aaron Fotheringham. He can flip, spin and hand-plant, all in a wheelchair.

"You always hear, 'Ah, he's in a wheelchair... oh, he's confined to his wheelchair,'" Fotheringham told CBS News. "I'm always like, I'm not confined, you know. I'm riding it like a skateboard or a bike. And I love it."

Fotheringham was born with spina bifida, a spinal cord defect that left him without the use of his legs.

Even as a baby, his condition didn't slow him down. A home video shows him crawling like he's late for something.

By age 8, he was learning tricks at the skate park.

In 2010, he landed the first-ever wheelchair double backflip.

"When I landed the double backflip, it was the best moment of my life," Fotheringham told CBS News. "When someone says you shouldn't or you can't, it kind of makes you want to do it even more."

That's why last year, he attempted California's so-called "Mega Ramp."

"You're in the air for so long and for me that's what it's all about. I'm just getting my frequent flier miles and having fun," Fotheringham said, referring to jumping the gargantuan ramp, then crashing back down to earth. "But landing is the hard part."

He's never down for long. Fotheringham is now a star performer in Nitro Circus, an extreme sports show. He goes by the nickname "Wheelz."

But it's at events with children, like one held recently outside Dallas, where Fotheringham really connects with fans. He has teamed up with volunteers to encourage children in wheelchairs to push the limits.

Eleven-year-old Luke Acuna, who lost his left leg when he was hit by a garbage truck three years ago, has learned an important lesson from Fotheringham. "Never give up," Luke said. "If you fall and you hit it really hard, get back up and do it again."

"There's just so much happiness floating around," Fotheringham said. "So it's cool seeing these kids how much they can accomplish and breaking all the stereotypes. It's rad."

Fotheringham is now thinking about the next trick that will impress an audience already captivated by the fact that while he cannot walk, he can soar.

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SBAGNE Needs Your Help!

We are in the process of updating our Membership database. In order to provide you with the most timely information and in the format you want, we need to make sure we have the correct information. During the month of September, you'll be receiving a phone call from a friendly SBAGNE representative. It will take only a few minutes to verify the information we have on file. Please accept our call so we can keep you informed.

2014 Walk-N-Roll

On June 7th and 8th, the Spina Bifida Association of Greater New England held our 5th Annual Walk-N-Roll for Spina Bifida at the Mass Hosptial School in Canton, MA, Stanley Park, Westfield, MA, Rock Church, Scarborough, ME and a new location in Manchester, New Hampshire. Over 250 participants from all over New England came out for this family-friendly event.

The Walkers and Rollers took on a 1.5 mile course and helped build awareness about spina bifida. Following the walk, Walkers and Rollers were able to connect with members of the community. This was not only a fundraising event, but a celebration!

The Walk-N-Roll for Spina Bifida is being held in various locations across the country to raise awareness about Spina Bifida and celebrate the accomplishments of the over 180,000 Americans living with it. All proceeds are used for programs and services for people living with Spina Bifida.

The name "Walk-N-Roll" was selected because it embodies a sense of inclusiveness and invokes the sense of empowerment which the spina bifida community embraces in all that it does. A belief in a better tomorrow is our vision and the steps taken in this walk represent steps on a path to realizing that dream.

Over $75,000 was raised for the Spina Bifida Association of Greater New England through the Walk-N-Roll for Spina Bifida. This is a remarkable amount!

Donations are still being accepted at **www.walknrollsbagreaterne.org**.

Thank you to all who participated and volunteered! You made the Walk-N-Roll a success!

Plans for the 2015 Walk-N-Roll for Spina Bifida are already underway. If you would like to be a member of the Walk-N-Roll Committee or would like to volunteer, contact

Thushy Muruges at **tmuruges@SBAGreaterNE.org**.

Annual Benefits Program

Visit SBAGreaterNE.org for more information and an application.

Apply today!

SBAGNE in the Summer!

Walk-N-Rolls, Picnics, Baseball with the Seadogs and Rock Climbing










For more photos, visit SBAGreaterNE.org!

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