SB® SBAGNE news

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

Notes from the Chair

Barbara Lee

Hello SBAGNE Members and Families,

It has already been a few months since we wished you a Happy New Year and the snow is gone! It is officially spring so we can hope for the sun and along the way some downright fun!

We are pleased to say that **BLING** was a huge success! Parents and daughters attended and there were new activities for everyone to participate in. We received some great feedback for future planning and the young women made new friends. The end of April will be **BEST** for the young men, where again we have lots planned for the weekend.

As you can see from our website the **Walk N Roll** teams are already 'rolling' out with their various fundraising events throughout our region. Please take time to see what events are taking place near you. Not to mention we are already over $10,000 at the time of this writing, which at this point is terrific! Once again we are going to strive to make our goals. Thank you all for your enthusiasm and support!

And in August we can cheer on the crowd at the **Falmouth Road Race**!! We have numbers to give to those who want to run or as with the Walk n Roll contribute to the team of your choice. A big shout out to **Dr. Estrada** who completed the LA Marathon and raised $2,200! Thank you Dr. Estrada, for your continued support to SBAGNE and for stopping by at BLING to say 'Hello'!

Remember that all that is contributed to these events go back to our programs and services throughout the year.

Thank you, sincerely,

Barbara Lee

Chair

Annual Benefits Program

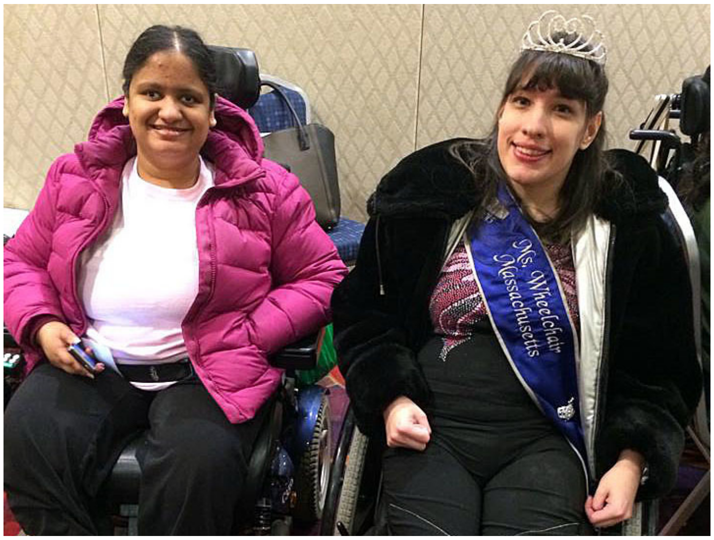
Visit SBAGreaterNE.org for more information and an application.

Apply today!

BLING

Better Living N' Girls

The 4th Annual Better Living N' Girls was held the weekend of February 28th at the Newton Marriott. The focus of the weekend was fun, education and socialization. Topics covered were bone health, college, skin care, spina bifida in Pakistan and wheelchair dancing. Saturday night included swimming in the hotel pool, dinner and a movie. The girls who were restricted from the pool with casts all hung their heads upside down in the pool. Teen girls will find a way! Check out the SBAGNE Facebook page and the back page of this newletter for pictures of the BLIN'G train, dancing and many smiles. Planning for 2015 is underway!



Save the Date!

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

Addressing Spina Bifida in Pakistan

Muhammad Mudassir

With a population of 184 million people, Pakistan is one of the most populous countries in the world. Approximately 114 million of the population lives in the rural areas. The overall literacy rate in rural areas is 49% and that of females is only 35% (Pakistan Economic Survey 2012-13).

Women in Pakistan, and particularly those in rural areas face many major challenges related to health and childbirth. According to Unicef, 250 out of every 100,000 women die during childbirth and only 43% of the Pakistani women get the supervision of a skilled medical attendant (Unicef Pakistan Statistics 2008-12). The childhood mortality rate is similarly alarming, also owing to the dearth of women's education and access to quality health care. In some tribal areas, women are limited to checkups with male doctors which is one of the major reasons why 69 out of 1000 children die before they turn 5 (World Bank Infant Mortality Rate 2009-13).

In Pakistan, one of the least recognized problems is Spina Bifida. Insufficient information is available regarding the Spina Bifida conditions in Pakistan, but according to an article published by Lady Reading Hospital Peshawar, Pakistan, "the incidence of Spina Bifida is 3-5 per 1000 births, but there are wide geographical variations ranging from 1-2 per 1000 to 4-5 per 10003" (Khan et al.,2006,p.243) .

The life of a person who has Spina Bifida in Pakistan is more than miserable. The lack of awareness, information and support makes it so much harder for both children and their parents to cope with the disease. As Spina Bifida is an incurable condition, parents require guidance at every stage of their child's development.

There are many factors that contribute to the increasing number of Spina Bifida cases, but the major cause is lack of awareness and education. Particularly the women in rural areas don't pay attention to the complications of the reproductive cycle, and the majority of deliveries happen at home and without proper prior tests and checkups. Consequently, it is not possible to predict any delivery complications or threat to the fetus in the womb.

A study performed by Lady Reading Hospital Peshawar, Pakistan in 2008 revealed that out of 3310 deliveries, 21 babies had hydrocephalus and 8 were born with Spina Bifida. The mothers of these babies reported that they had not taken folic acid in their first months of pregnancy.

This shows that there is a great need to bring awareness about Spina Bifida to the general public in Pakistan. Women in general have no idea about the importance of consuming folic acid and B-vitamin before and during pregnancy. They don't know the fact that both of these dietary components can reduce the chances of Spina Bifida in their children up to 70%.

In Pakistan, the real distress for parents indeed starts after the child's surgery. Unfortunately, there is not a single organization dedicated to Spina Bifida or Hydrocephalus. Parents require information about issues related to the disability, post-surgical rehabilitation, physiotherapy, exercises, issues relating school life, and many other important matters- but no one is there to give them a no-cost solution. In the last decade, the urologic care for Spina Bifida children has advanced, with many improved protocols, but there is no channel for that information to reach patients and their families.

There is a great need to establish an organization dedicated fully to Spina Bifida in Pakistan, which will light the first candle in the dark lives of the people living with this difficult and pervasive disease.

***Muhammad Mudassir** works for United Bank Limited Pakistan and is currently pursuing a year of professional development under the Hubert H. Humphrey Fellowship Program. The program is sponsored by the U.S. Department of State's Bureau of Educational and Cultural Affairs and administered by the Institute of International Education (IIE). He plans to establish the Center for Spina Bifida and Hydrocephalus in Pakistan on his return. Muhammad can be reached via email at **m.mudassir@hotmail.com** or cell (**+1-978-876-9552**)*

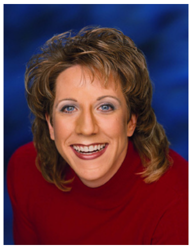
Khan, Khan., and Ahmed. 2006. Short Term Outcome of Surgical Management of Patients with Neural Tube Defect (Spina Bifida).

Adaptive Sports Experience

Abigail Bemis

Recently, I have been able to participate in adaptive sports activities. So far, I have done so rock climbing, cross-country skiing, snowshoeing, and kayaking, all adaptive. I especially enjoy rock climbing and snowshoeing. I participated in snowshoeing with Waypoint Adventure, sponsored by SBAGNE. Snowshoeing was a new experience for me. I did try the snow shoes, but then used a sit-ski for the rest of the time. It is something I would do again. Kayaking, also with Waypoint Adventure and sponsored by SBAGNE, is something I would definitely do again, maybe in the summer. Going last summer was a very enjoyable experience that I would gladly to again. I really enjoy rock climbing. I usually go about once a month. I enjoy trying out the different walls. It allows me to get active and have fun. I am also excited to try out any new adaptive sports when the opportunity comes. :-)

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 SBAGNEs 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. Applications are due by May 16, 2014.

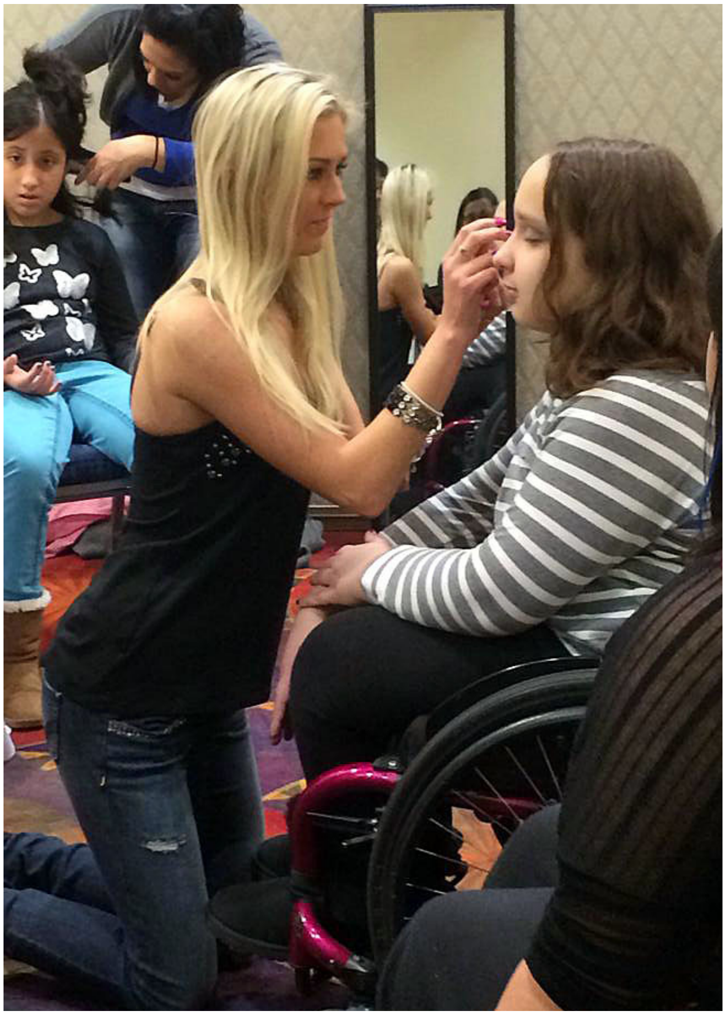
WALK-N-ROLL®
for Spina Bifida

4 Locations in 2014 !!!!

June 7th, 2014
Canton and Westfield Mass.
Scarborough Maine

June 14, 2014
Manchester New Hampshire

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
or contact
Thushy
tmuruges@SBAGreaterNE.org



Getting Active with SBAGNE, Waypoint Adventure and Spaulding Rehab

Abigail Bordeaux

Exercise. We know it's important, but that doesn't usually make it any easier to get started. This cold winter was especially challenging for me since I keep my exercise equipment in an unheated space - brrrr, no thanks! Even though using my hips and legs as much as possible and doing my prescribed strengthening exercises help eliminate pain in my hip, the past few months have been a struggle.

Fortunately, SBAGNE's February winter hike and snowshoe event with Waypoint Adventure coincided with a rare warm up to above freezing and the sun even came out. The Waypoint team came with adaptive equipment, including sit-skis, in keeping with their mission to provide adventures to people of all ages and abilities. Not only were all of us able to enjoy the beautiful Assabet Wildlife Refuge in Sudbury, we built community and learned the 10 essentials to pack when going out in the woods. And going out with a group of people was much easier and enjoyable than exercising alone.

A few weeks after our hike, I participated in a Spaulding Adaptive Sports Centers-Waypoint indoor rock climbing event, something I had never considered until one of the other hike participants mentioned it. I'm so glad I tried. It's rewarding to learn that you can do something you always thought of as "for other people." Waypoint has several different climbing equipment choices for upper and lower body support, so whatever your needs and abilities they have options for you, and the team of staff and volunteers will cheer you on.

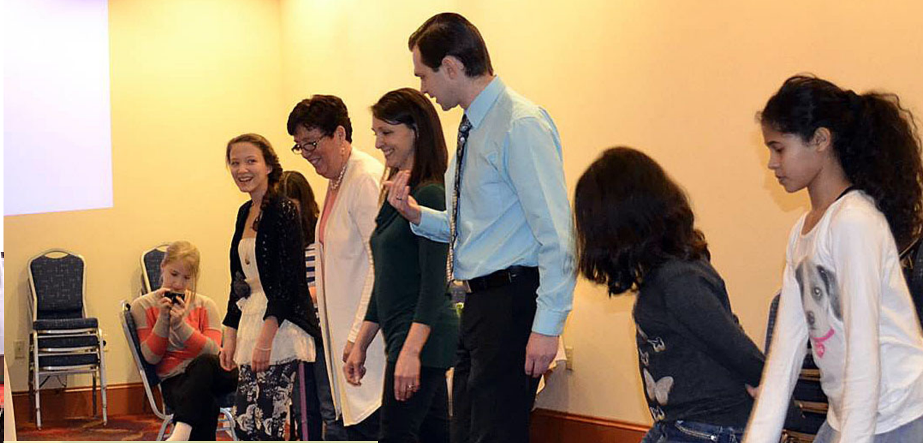
The Waypoint team is skilled, helpful, and fun to spend time with. SBAGNE has received a new grant to partner with them on future Get Active! programs, so watch this space, the website, and/or Facebook for more information and sign up for the next Waypoint/SBAGNE adventure!

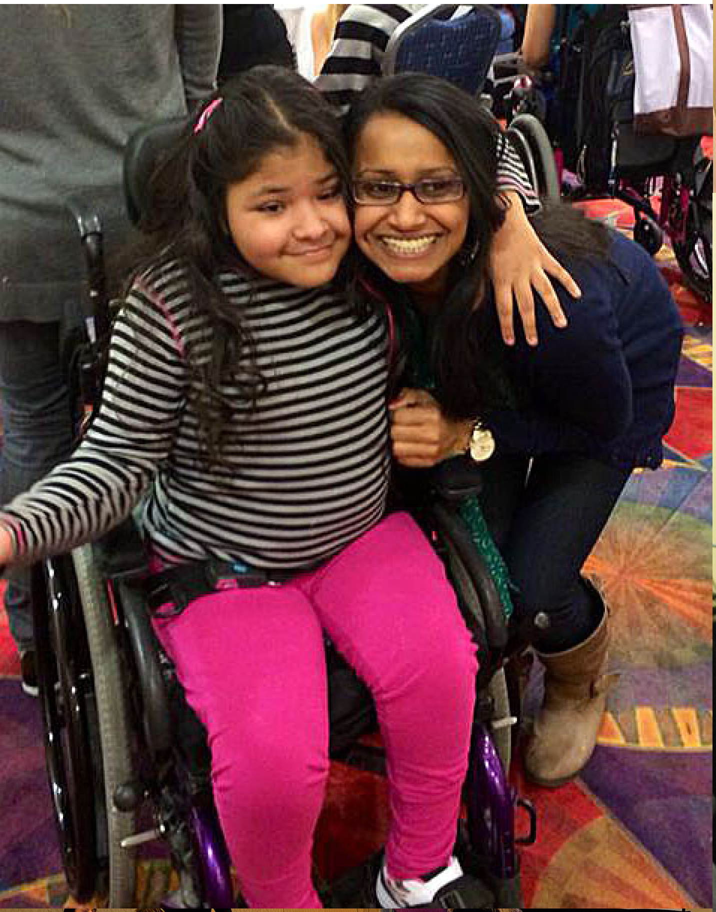
More resources

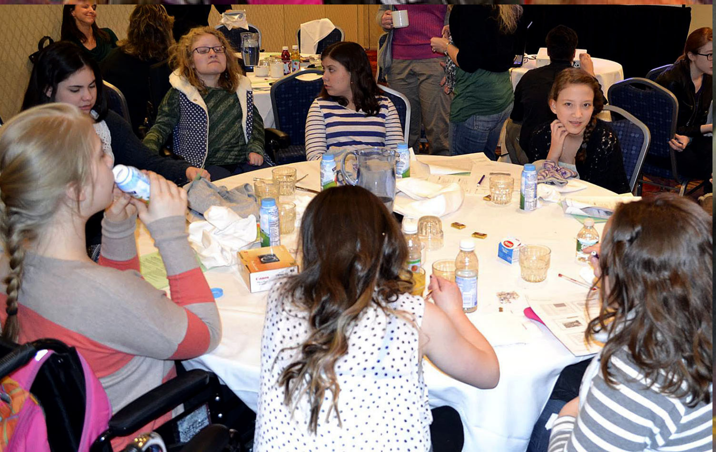
- Waypoint Adventures: http://waypointadventure.org Waypoint partners with many organizations, including SBAGNE, and offers some open enrollment activities.
- Spaulding Adaptive Sports Centers: 877-976-7272 SASC runs a variety of fee-based adaptive sports activities.
- SBA's Health Guide for Adults Living with Spina Bifida (available to all SBAGNE members) has many more tips about getting active as well as a long list of recreation resources.

BLING

Better Living N' Girls







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