



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

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SBA of NENY News to Use

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SBANENY

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MESSAGE FROM THE CHAPTER CHAIR

As 2011 reaches its end, I am writing the newsletter's "letter from the chair" for almost certainly the last time. After well over 15 years of involvement with the local Spina Bifida chapter, and several terms as "chapter president" (under the old by-laws) and "board chairman" (under the new), I will be turning over the chairmanship reins to Shameka Andrews in January. I wish her the best of luck! While my term as director has another year to run, this office "retirement" comes with no small relief but also with a degree of regret and a considerable amount of nostalgia.

Back when my wife Vanessa and I first became involved with the local Spina Bifida association with our son (now nearly 22! How on earth did THAT happen?!?), the chapter governing body was almost entirely made up of parents of children with Spina Bifida. That was only to be expected since the organization was essentially a support group for those same people. We provided what community services we could, given our resources, and met for meetings at one another's homes. It was as much social as anything else, and we enjoyed it for what it was.

Ten years ago, we hired Karen Wentworth as our executive director and in so doing took a giant step toward being the professional organization we now strive to be. Karen is still providing the incredible amount of support that we now take for granted; if there is one person responsible for making SBANENY what it is today, she is that one.

Today, we have an actual office, a web site (www.sbaneny.org), interact with legislators, and offer numerous programs utilizing a budget we would have marveled at back when. Our current board still contains some SB parents but they are a minority: most are people who actually have Spina Bifida or are community members with no direct ties to SB. The latter make up fully a third of the board and that percentage is growing.

I'd like to take this last chance to thank all my co-directors (current and past), Karen, and all the people that I've had the pleasure to meet during my tenure. It's been quite a ride at times!

Kevin Chamberlain
Chapter Chair



CABIN FEVER PARTY!

You may remember that last summer we tried twice to hold a SBANENY picnic – once to be rained out by Tropical Storm Irene, and the second time to be blockaded by the results of flooding & storm damage. We have not given up! Since the picnic plan needed to be delayed, it was decided to do the summer picnic – with a twist! So... Here are the plans for a SBANENY Cabin Fever Party!

Who: Individuals of all ages with SB & their families (parents, siblings, spouses, children, caregivers)

What: Getting to know you picnic
Food, beverages, games, crafts, activities, fun!

When: Saturday, March 3, 2012, Noon to 4 PM

Where: The Crossings of Colonie
580 Albany Shaker Road
Loudonville, NY

Fee: \$5/adult, 14 & under free!

Please RSVP by February 27th.
Reservation form enclosed

SBANENY GOES TUBING

AT

WILLARD MOUNTAIN

Who: Family & Friends of SBANENY

What: Tubing, pizza, hot chocolate, board games

When: Sunday, January 15, 2012

Time: 5 to 8 PM

Where: Willard Mountain, Easton, NY (45 minutes northeast of Albany)

Suggested Donation: \$12/person,
Under 5 pay your age!

Please RSVP by January 11th.
Reservation form enclosed.

SBNENY SPONSORS SPINA BIFIDA CONFERENCE

**“EXPAND YOUR HORIZONS
THROUGH
HEALTHY LIVING”**

Who: Individuals with Spina Bifida, families, caregivers, & service providers

When: Saturday, April 28, 2012

Time: 8:30 AM to 5 PM

Where: Bryant & Stratton College, Albany, NY

Keynote Speaker:

James H. Rimmer, Ph.D., is a Professor in the Department of Disability and Human Development, College of Applied Health Sciences, at the University of Illinois at Chicago. For the past 25 years, Dr. Rimmer has been developing and directing health promotion programs for people with disabilities. He is director of two federally funded centers, the National Center on Physical Activity and Disability (www.ncpad.org) and the Rehabilitation Engineering Research Center on Recreational Technology and Exercise Physiology (www.rerectech.org).

Other Highlights:

The conference planning committee has arranged for experts to speak in the areas of neurology, urology, aging & SB, self defense, and adapted exercise. More topics to be announced in the near future.

Watch your mail and email for more conference information and registration forms!

Save April 28th on your 2012 calendar today!

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SPINA BIFIDA FAMILY RETREAT WEEKEND AT DOUBLE H RANCH

The weekend of October 21st was a remarkable event for a large group of families as we gathered at Double H Ranch. We had 17 families including over 70 people in attendance, some who had attended the weekend before and some joining us for the first time.



Brittany masters the cargo net at the ropes course.

On the surface, you could say that we played. Family members enjoyed campfire songs and an ice cream social Friday evening. Saturday was busy from start to finish with ice breaker games, followed by enjoying the Ranch activities. There were fish to be caught, ropes to climb (and master!), small animals to pet, science projects to explore, crafts to be made, archery targets to be hit, pumpkins to be carved, and of course the Halloween Party!

In reality, much more than that took place. Parents connected with other parents, sharing information, tips, resources and support.



Children with SB and their siblings made new friends and

Parents & siblings made connections during the weekend activities.



renewed old friendships, creating opportunities for a growing support network in their future. Those in attendance summed it up best as they each shared one word that described their experience from the weekend; "awesome, heartwarming, fun, friendship, community, and family" were a few of the descriptive words people offered.

Spina Bifida Family Retreat weekends are held at Double H Ranch toward the end of October. They are open to individuals with SB between the ages of 5 & 21 and their families. Plan ahead for next year!



Making magic mud is a gooey experience!

Jordan, how much food can a guinea pig can eat?



With a little help from the costume room, everyone was dressed for the Halloween party!



ASK THE YOUNG ADULTS!

In June, three of our young adults with SB met with a group of parents to share their experiences and thoughts about what has been helpful to them as they have grown up with this disability. Thank you to Bryan, Heather & Lyndsi, for your willingness to assist parents of our younger children. As part of the program, they agreed to allow their answers to be published in our newsletter for the benefit of all. The following is an excerpt from that program.

Q: What was helpful that your parents did for you?

The thing that really helped for me is that my parents never made my disability an excuse for *anything*. If I wanted to play softball, that's what I was going to do. If it needed to be adapted, fine. They didn't set any limitations. Adaptation doesn't mean limitation.

Right from the get-go my parents told me there's nothing I couldn't do. They said there are things we may need to help you with along the way but you are going to be as independent as possible. I was able to do that because I became gradually more independent. If you teach that over the course of the years, your child will be ready.

There was a lot of tough love. Sometimes I just felt "Aw, why can't you just do this for me?" But now I really appreciate that because I can do things on my own.

Q: What are some of the things that your parents did for you at younger ages that helped? For instance in the elementary age years?

A lot at that age was medical stuff – cathing and stuff like that. The more independent you can get with this, the more things you will be able to do. Knowing things as a child also helps you to be your own advocate.

Being able to go to your parents and ask for help and guidance was important.

Knowing about Spina Bifida is really important. Your child will get people who will ask. Being able to have an answer that is appropriate given the situation is really important. Knowing about themselves will help them. Know what it is that they have, even at a very young age. That's really important.

Younger children might not be comfortable answering. Teaching them what to say when they don't want to explain is also important.

MY EXPERIENCE AT SBA NATIONAL CONFERENCE

BY SHAMEKA ANDREWS

In the last edition of the newsletter, Shameka shared some of her experience that she had at the SBA National Conference in June. Here are more thoughts that Shameka would like to share.



Shameka about Advocacy: There are lots of people that spend lots of time and money to make sure that people with SB and their families get the services and programs they need and it is important that those who benefit from these programs advocate so they continue.

Advocacy is so important especially nowadays when so many programs are getting cut. The people that benefit from these programs, people with SB and their families, need to speak up and be heard. I know speaking up can be very scary for some people but we have people that are a part of our board that can help find out who your representatives are, how to make appointments to meet with them and will even go with you to meet with them. National SBA has developed a program called SPEAK for Spina Bifida. If you want to learn more about this program and how to get involved, contact the chapter office or visit the national website at www.sbaa.org.

I urge everyone that benefits from the Spina Bifida Association of NENY (SBANENY) and National SBA programs to get involved.

ARE YOU PURSUING AN EDUCATIONAL OR TRAINING GOAL?



HELEN R. MERTENS EDUCATIONAL SCHOLARSHIP FUND

SPONSORED BY SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK

The purpose of the Helen R. Mertens Scholarship is to award financial assistance to persons who have Spina Bifida and are pursuing higher education, technical training, or driver's education. The amount of the grant is a maximum of \$500 for this fiscal year. It is intended to be used toward the cost of tuition, fees, and books. The exact amount to be disbursed will be at the discretion of the Scholarship Committee. The number of scholarship applicants will be a factor in this decision.

Eligibility Requirements:

1. Applicants must have Spina Bifida or a spinal cord disability resulting in similar challenges.
2. Applicants must reside within the geographic region served by the Spina Bifida Association of Northeastern New York.
3. There is no age limit.
4. Applicants must demonstrate acceptance by a school of higher education, technical training, certificate program, or driver education training program.
5. No financial statement shall be required.

Application Deadline:

The deadline for receiving applications and all supporting materials is the close of business, March 30, 2012.

If you are interested in receiving further information, or would like to obtain a copy of

the scholarship application, please contact our chapter office.

We are grateful to Helen R. Mertens and her estate for making this scholarship program possible for our chapter.

MEDICAL MANAGEMENT OF SPINA BIFIDA

Dr. Brad Dicianno, physiatrist who runs University of Pittsburgh's adult Spina Bifida clinic and is on national SBA Professional Advisory Council, is one of the few experts in issues facing adults with SB in the country. He also has done the most recent research on secondary conditions affecting folks over age 35 who have SB. He presented to constituents over 40 at the national SBA conference last year.

Specific to cholesterol, recommendations are as follows:

- Should be checked at age 20 for a baseline.
- Men over age 34 should also be checked every 5 years.
- Women over age 44 should also be checked every 5 years
- Total Cholesterol should be less than 200
- HDL is "good cholesterol" and should be higher than 50
- LDL is "bad cholesterol" and should be less than 130
- or in some cases less than 70
- Triglycerides should be less than 150

Separate from genetics (which cannot be changed), a diet high in red meat, and low or no exercise, as well as aging are all factors that affect cholesterol levels. From that perspective people with SB –especially those who are non-ambulatory, are at higher risk for high cholesterol. Regular monitoring with their GP is advised.

If you are interested in reading Dr. Dicianno's recent publication on issues facing adults over 35 years old, please contact the SBANENY office.

411 ON DISABILITY DISCLOSURE: A WORKBOOK FOR YOUTH WITH DISABILITIES

[HTTP://WWW.NCWD-YOUTH.INFO/411-ON-DISABILITY-DISCLOSURE](http://www.ncwd-youth.info/411-on-disability-disclosure)

This workbook, available online at no cost, is designed for youth and adults working with them to learn about disability disclosure. It helps young people make informed decisions about whether or not to disclose their disability and understand how that decision may impact their education, employment, and social lives. Based on the premise that disclosure is a very personal decision, the Workbook helps young people think about and practice disclosing their disability.

The workbook does not tell a young person what to do. Rather, it helps them make informed decisions about disclosing their disability.

TIPS ON EMPLOYMENT RIGHTS

The Americans with Disabilities Act (ADA) protects your rights to equal opportunity for jobs and services. It does so by prohibiting many different kinds of discrimination against people with disabilities. Where employment is concerned, the law says that:

- An employer is not allowed to ask you about your disability during an interview or make you take a medical exam. (You do not need to include information about your disability on your resume or job applications.)
- An employer may ask if you can perform specific job functions or activities. For example, could you deliver pizzas? Clear Tables? Run a cash register?



- An employer must make reasonable accommodations (changes) for your disability. For example, you might need to sit instead of stand to operate a cash register. Or you might need an accessible bathroom.

You will want to share your needs with your employer so that reasonable accommodations can be made. A great resource is the Job Accommodation Network (JAN), www.askjan.org. A service of the Office of Disability Employment Policy, JAN is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. Check out the Web site for "Ideas for Writing an Accommodation Request Letter."

You might arm yourself with useful information about accommodations that you can share with a current or potential employer. For instance, most accommodations are very simple.

Surveys of employers who used the Job Accommodation Network show that 50 percent of all accommodations cost from \$0 to \$50 and 88 percent of all accommodations cost less than \$1,000.

Also, tax incentives can provide an added benefit for employers by offsetting costs associated with accommodating an employee or making their businesses accessible. These benefits include: work opportunity tax credit – up to \$2,400 per year; small business tax credit – up to \$5,000; and tax deduction to remove architectural and transportation barriers to people with disabilities and elderly individuals – up to \$15,000 per year.

This article was reprinted from Insights Into Spina Bifida®, the Spina Bifida Association's national magazine. To order a subscription to Insights, please visit www.spinabifidaassociation.org.

SBANENY DEVELOPMENT UPDATE

GO TO THE THEATRE FOR SBANENY!

This fundraising event is critical to the financial management plan for our chapter.

Please do what you can to help. Here are some options:

- purchase tickets to attend;
- help with publicity by making copies of the enclosed order form and giving them to family and friends;
- put the event on your Facebook
- send out emails with information to friends & family

We need your help to make this a successful fundraising event. Thank you.

LOVING HANDS IN ALL SEASONS QUILT GUILD STITCHING BLOCKS FOR SPINA BIFIDA

Raffle tickets may be purchased:
\$1 for one ticket
\$5 for six tickets

Call or email our office today!



SBANENY 2011 MOHAWK HUDSON MARATHON UPDATE **Runners Raise Awareness & Funds for Spina Bifida!**



*Caroline Barrett, Annie Riker,
Jennifer Gallagher & Katie Gallagher*

In addition to Jen's team above, we also had two other people running for SBANENY; Oein O'Riordan and Jim Gallagher. We are grateful to all of our runners who not only trained hard for a great marathon day, but also worked hard to raise over \$6,000 for to support SBANENY programs and services.



SBANENY WALK-N-ROLL FOR SPINA BIFIDA

The SBANENY Walk-N-Roll for Spina Bifida is being planned for spring of 2012. Committee planning meetings will begin in January. The committee needs your help to make this a successful event. Please call or email the SBANENY office as soon as possible. We look forward to the 2012 Walk-N-Roll for Spina Bifida and welcome your help to plan and organize it!



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RETURN SERVICE REQUESTED

DECEMBER
December 15

SBANENY Goes to the Theater!
Man of La Mancha
at Capital Repertory Theater

2012
JANUARY
January 15

Tubing at Willard Mountain

MARCH
March 3

Cabin Fever Party, The Crossings, Albany

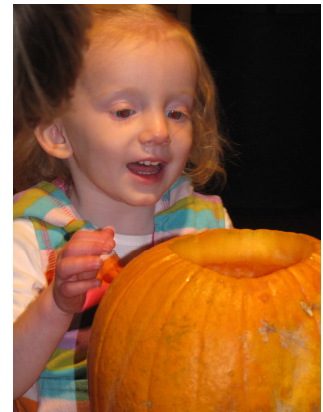
APRIL
April 28, 2012

Spina Bifida Conference, Albany
"Expand Your Horizons through Healthy Living"

SPRING
Date TBA

Walk-N-Roll for Spina Bifida

Programs for adults and parents with children are in the planning stages. Please watch for flyers and emails with information coming early in January.



Carving pumpkins is a popular annual tradition at Spina Bifida Retreat Weekend.



TUBING AT WILLARD MOUNTAIN!

Date: Sunday, January 17, 2010

Time: 5 – 8 PM

Place: Willard Mountain, Easton, NY (45 minutes NE of Albany)

Suggested Donation: \$12/person,
5 & Under – pay your age!



*Tubing -- a relaxing
ride for Alexa!*

Price includes 3 hours of tubing, pizza & drinks. Please bring a snack or cookies to share.

(Please note: We do not wish to exclude any individual or family because of the suggested donation of attending. If you are unable to pay the suggested fee, please send an amount that you feel you are able to afford.)

- Make checks payable to SBA of NENY.
- Mail checks with this form to 123 Saratoga Road, Scotia, NY 12302.

RSVP is required! Deadline for RSVP is Tuesday, January 12, 2012

Bathroom Facilities Note: This year we will be eating our pizza and tubing all from the Tubing lodge (to the right when you pull in the parking lot). There is only a port-a-potty there. If you require less rustic bathroom facilities, there are accessible bathroom facilities in the main lodge (to the left when you pull in the parking lot).

Tubing at Willard Mountain RSVP – due by January 12, 2012

Family Name _____

# of adults _____	X \$12 =	\$ _____
# of children (ages 6 – 17) _____	X \$12 =	\$ _____
Ages of Children 5 & Under _____	add their ages =	\$ _____
	TOTAL	\$ _____

SBANENY Cabin Fever Reservation – by Feb 27th

Name: _____

Address: _____

Email: _____ Phone: _____

of Adults _____ X \$5.00 Total Enclosed \$ _____

Ages of children _____



Please make checks out to Spina Bifida Association of NENY and mail to 123 Saratoga Road, Scotia, NY 12302