



TABLE OF CONTENTS

***ADULTS: SKILLS FOR EMPLOYMENT**

***PARENTS: BUILDING INDEPENDENCE** Page 2

***EMPOWERMENT... POST CONFERENCE SURVEYS**

***SPINA BIFIDA RETREAT WEEKEND**

***HELEN R MERTENS SCHOLARSHIP PROGRAM** Page 3

***ADAPTIVE YOGA ***

*** PROPER SEATING & WHEELCHAIR FITTING** Page 4

***ADA STANDARDS**

*** CYBER DISCLOSURE WORKBOOKS** Page 6

***WALK & ROLL FOR SB**

***SBANENY GOES TO THE THEATER A HIT!** Page 7

SBANENY CALENDAR OF EVENTS Page 8

MESSAGE FROM THE CHAPTER CHAIR

The year 2010 was a very successful one for SBANENY! The high point for many was our first regional conference held last October. The one day conference offered a number of wonderful speakers addressing a variety of issues of interest to our SB constituency and was given nearly unanimous approvals. It was the culmination of literally years of work. For those that attended -- and especially for those that did not! -- we are already working toward our second conference, tentatively scheduled for Spring of 2012.

Our very much appreciated Executive Director, Karen Wentworth, reports that our support activities continued to expand. Some examples include working to supply information and resources to a school administrator addressing the educational needs of students with SB so that staff might better serve affected students; working with parents to find community resources to help their families with the impact that SB is having on them; working with adults with SB of varying ages to help them connect with resources in the community. (One of the unexpected outcomes of October's conference was that the attendance of a number of adults with SB drove home the need for more adult programming; you should be seeing the result of that this year.)

We have also offered and participated in a number of awareness campaigns, including conversations with our legislators, but obviously have a long way to go!

Family events remained an important aspect of Chapter programming. Tubing at Willard Mountain last year (and even more so last month) was very popular, as were the annual fall retreat at Double H Ranch and our night at Capital Rep to see *A Christmas Story*. The latter turned out to be not only a fun evening, but – because of the great turnout – it was also a highly successful awareness vehicle and fundraiser. And no one shot their eye out!

On the more mundane side, the Chapter has been working increasingly with our National office. Together, we are becoming better organized and more effective in our common mission. Also, our Chapter welcomed new directors Stephanie Bartkowiak, Amy Clinton, and Dan O'Connell, who bring valuable and much appreciated skills and insights to the board.

Finally – speaking of appreciation – I would be seriously remiss if I didn't take this opportunity to thank outgoing chair Barb Devore for the incredible job she has done at the helm of SBANENY for the last several years. Her ideas and tenacity have strengthened the chapter immeasurably. (Don't fret; she's not going far!)

SBA of NENY Board of Directors

Kevin Chamberlain, Chair
Shameka Andrews, Vice-Chair
Raymond Langelier, Treasurer
Dan O'Connell, Secretary
Barbara Devore, Past Chair
Jennifer Gallagher
Stephanie Bartkowiak
Amy Clinton
Hali Holmes
Stefon Stilwell

**Kevin Chamberlain
Chapter Chair**

SBANENY CHAPTER PROGRAMS & ACTIVITIES

ADULTS!

HEALTHY LIVING:

EXERCISE AT HOME

PRESENTED BY NED NORTON OF WARRIORS ON WHEELS

January 29, a group of our adults met with Ned Norton of Warriors on Wheels to learn about Exercise at Home. Mr. Norton worked with the group on a variety of exercises and inexpensive household items that can be used for strengthening. The group left invigorated and with a healthy feeling that they had been using their muscles!

NEXT ADULT PROGRAM – SKILLS FOR EMPLOYMENT:

In addition to the presentation, the group also brainstormed a variety of presentations and activities that they would recommend for adults in our community. With those ideas in mind, the next program will be Skills for Employment; interviewing, resumes, and applications. The program is in the planning process. **Watch your mail and emails for announcements with details!**



SBANENY IS ON

FACEBOOK!

Visit our page, post SBANENY and Spina Bifida related messages, pictures and suggestions.

PARENTS!

BUILDING INDEPENDENCE:

HOW TO DEVELOP BETTER ATTENTION & INITIATION

Some children with Spina Bifida instantly react to proposed activities with a “no” because it makes them feel uncomfortable on the inside. This presentation of SB University addresses typical concerns that parents have about this. Have you seen this in your child? Do you have questions and concerns about how to best address this with your child? Come to our next program for parents... Watch the presentation with the group, share ideas with other parents and learn skills that will help your child to work through their “no” reactions!

Presentation: Parents will view & discuss “*Building Independence: How to Develop Better Attention & Initiation*”

Participants will learn to:

- Identify characteristics of poor attention and poor initiation based on observable behaviors;
- Identify supportive activities at home and school to help a child develop improved initiation and attention;
- Describe environmental modifications at home and school to help the child be more successful and;
- Explain the link between physical activity and the development of brain based skills.

Date: Saturday, April 9, 2011

Time: 10 AM – 1 PM

Place: Meeting location to be determined

Childcare: Available for parents attending the presentation

Pizza Lunch: Served at Noon

Advance Registration Required.

Watch your mail and emails for announcements with further details!

➤ **DISCLAIMER:** SBA of NENY does not endorse or recommend products, services or manufacturers and assumes no liability whatsoever for the use or contents of any product or service mentioned herein. The information provided in this newsletter is for information, educational and entertainment purposes only. It is not intended as medical or professional advice.

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, April 29, 2011.

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.

SPINA BIFIDA FAMILY RETREAT WEEKEND AT DOUBLE H RANCH

Date: October 21 – 23, 2011

Time: 6 PM Friday to Noon Sunday

Place: Double H Ranch, Lake Luzerne, NY

Who: Child with SB (must be aged 5 to 21) and their immediate family.

All participants must submit the necessary Double H applications by October 7, 2011. Registration forms will soon be available to download at www.sbaalbany.org.

EMPOWERMENT THROUGH INFORMATION:

LIVING WITH SPINA BIFIDA

FOLLOW UP SURVEYS

Everyone who attended our October 2, 2010 conference was asked to complete an evaluation at the end of the day. We are now requesting that you complete a follow up survey so that we can learn what the long term impact of the conference has been for you. Collecting this information is critical to the conference planning committee.

- **We need this data to comply with requirements from grants** which were used to support Empowerment through Information: Living with Spina Bifida.
- **Data gathered from people who attended October 2nd will guide the Conference Planning Committee** as they begin plans for a future conference.
- **Post surveys are tools that can be used to support applications for future grants.** The data that we gather with this evaluation will be valuable in grant applications for a future conference or chapter programs.

RESOURCES & INFORMATION....

If you attended the conference, you should have received a follow up survey in the mail. If we have your email address, you would have received one by email as well.

If you have yet to respond, please take a few minutes today to give the SBANENY Conference Committee your feedback. Planning for the next conference is in the very beginning stages. Input from all who attended in October will help to make the next chapter conference event even better! Can't find your survey? Contact our office and we will be happy to send another out to you!

Thank you to everyone who has returned their completed surveys.

ADAPTIVE YOGA

The Center for Disability Services in Albany offers an adaptive yoga class once a week. We recommend that you call in advance and speak to Rich Vassi at 437-5714 if you are interested in learning more about this program.

Where: Center for Disability Services
314 South Manning Blvd, Albany

Time: Monday evenings, 5:30 – 6:30 PM

Who: Adults ages 18 and over

Fee: \$5/class

Registration: Prior to first time attendance

SBANENY FAMILIES HAD A BLAST TUBING AT WILLARD MOUNTAIN!

This year's tubing event was the best yet! We had a great group of people ranging in age from preschool age to those not quite so young. The mountain was fast, the pizza and hot chocolate a nice break from the cold, and the dessert treats were outstanding! Many thanks to the folks at Willard Mountain for the opportunity to offer an affordable fun event for SBANENY's families and friends.



SPINA BIFIDA UNIVERSITY OFFERS EXPANDED OPPORTUNITIES FOR LEARNING

SB University, or SBU, is a new program from Spina Bifida Association which shares unique educational opportunities in an online format. A series of taped sessions from the 2010 Conference are being released online. These sessions cover a variety of topics from urology to education to aging with Spina Bifida.

For more information or to see the schedule of upcoming sessions, visit www.SBUniversity.org.

ASK THE EXPERT: TIPS FOR ADULTS PROPER SEATING AND WHEELCHAIR FITTING By Cody Verrett, ATP – ATG Rehab

Why is it imperative that a seating system fit correctly?

An accurate fit is incredibly important for both physiological and functional purposes. The basis of any seating system is that it provides both comfort and postural support, and without it fitting correctly these two essential elements can be compromised. When there is a problem, generally it is because the equipment is appropriate but the person wasn't fitted properly. Problems such as pressure sores may not surface right away but may develop six months to a year later.

What experts should be involved in a seating and wheelchair evaluation?

A team approach often yields the most successful outcomes for seating and positioning for mobility. The key participants in an evaluation of this type are a clinician – either an occupational therapist (OT) or physical therapist (PT) with experience in ordering equipment – and a complex rehabilitation equipment provider who is a certified assistive technology professional (ATP). In 2008, the Centers for Medicare & Medicaid Services (CMS) began requiring ATP certification for assistive technology providers, marking the first time providers were legally required to have certification to provide equipment. Many OTs and PTs also pursue this certification even though

they are not required to do so. For a list of ATP-certified clinicians and assistive technology professionals in your area, check out www.resna.org.

What is involved in a proper evaluation?

A review of past medical history and thorough mat evaluation by a clinician is a critically important first step in a proper evaluation, as they help to identify a person's range of motion, muscle tone, skeletal deformity, postural control, and balance. Accurate body measurements to ensure an accurate fit are often the next step in the process. Then the individual tries out different products and components to determine his or her preferences. An assessment of the person's home and work environments is important too, to ensure the wheelchair will enable the individual to successfully navigate in those areas.

The easiest way to make sure the wheelchair fitting is done right the first time is to have as many samples and seating components on site as possible so the individual can test the wheelchair at the clinic. This allows therapists to see and educate the patient as to what will work and what possibly might need improvement. "Seating Clinic" is a term that typically indicates a clinic offers a high level of expertise from both clinicians and equipment providers who offer personalized service. These types of places usually have a wide variety of products and accessories on-site to try out.

Technology has made it much easier for therapists to properly identify a wheelchair system for long-term care that greatly reduces the risk of pressure sores. Pressure mapping systems can be useful as part of an evaluation to compare existing and new cushion choices in order to prevent potential problems. The mapping system includes a thin mat that is placed on top of the wheelchair seat cushion and is connected to a computer. The software allows therapists to see exactly how much pressure is being applied to various areas. Pressure mapping systems can visually depict what may not be able to be felt, such as areas of unacceptable pressure or inadequate weight displacement across the surface.

How often should I get an evaluation, and will it be covered by insurance?

Evaluations are typically covered by insurance. Generally speaking, wheelchairs are only replaced after a minimum of five years of use and 18 months to two years for cushions. However, any time an individual's medical condition, comfort, or functional ability changes, he should consult his physician since these indicators would justify an evaluation and should be covered by insurance.

It's difficult to stay up-to-date on what products and accessories are available. Any advice?

Not all clinicians have training in seating and positioning for wheeled mobility, so it is important for an individual with Spina Bifida to be a proactive and knowledgeable participant in the process. The individual should also seek out references to find and work with a team of professionals who specialize in these devices. For people with Spina Bifida who want to stay up-to-date on options, www.abledata.com is an unbiased and widely recognized hub for information about products and services for individuals with disabilities. In addition, there are Abilities Expos held in several locations around the country on an annual basis for individuals to learn more.

What are some useful new accessories on the market that people may not know about?

Products are constantly evolving into more advanced solutions for individuals with Spina Bifida. For instance, Quickie Wheelchairs recently released a new rigid chair named the Q7 that is getting rave reviews for its strength and ride qualities. In seating and positioning, two new foam and air cell hybrid cushions hit the market recently – one from Quantum Rehab called the Spectrum Air and another from ROHO called the Hybrid Elite. Both offer the pressure-reducing properties of air cells, but add stability through their foam support bases.

What can I do to maintain both my chair and the fit?

If you find that you are uncomfortable sitting in your chair and it's within the first year or two, chances are good that your insurance will cover another evaluation and your warranty may cover new seating components. Insurance companies do not readily replace these expensive devices, so care is essential for long-term success (although they are much more liberal in replacing parts such as cushions). A person with Spina Bifida needs to understand that equipment has a shelf life and own the responsibility for maintaining the fit and chair over the long haul. Take good care of your equipment. For instance, don't keep a manual wheelchair that you transfer in and out of on the front porch. It will get wet and the bearings rust. Little things like this can help extend the life of the chair.

Cody Verrett is Vice President of Sales and Marketing for ATG Rehab, a mobility and seating solutions provider, and formerly worked as a national sales manager, product manager, director of education, and rehab technology supplier. For more information visit atgrehab.com or visit ATG Rehab on Facebook.

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.

EXCEPTIONAL PARENT DIGITAL JOURNAL

American Association on Health & Disability (AAHD) is offering a one year free subscription to Exceptional Parent Digital Journal to AAHD Members & Colleagues. EP Digital Journal is the former Exceptional Parent Magazine. The publication provides resources and educational information for families of children and adults with disabilities as well as to physicians, allied health care professionals and educators, and advocates. If you are interested in receiving EP Digital Journal, go to <http://www.surveymonkey.com/s/epdigitaljournal> or call 301-545-6140.

ADA STANDARDS FOR ACCESSIBLE DESIGN

The 2010 ADA Standards for Accessible Design are now available online through the Justice Department. The standards were adopted as part of revised regulations for Title II and Title III of the Americans with Disabilities Act of 1990. Go to www.ada.gov/2010ADASTandards_index.htm for details.

The standards go into effect on March 15, 2012. They will set minimum requirements for new construction and alterations of facilities of state and local governments as well as businesses. These revised standards will require affected building projects to be made accessible for the more than 54 million Americans with disabilities. This offers one resource for architects, contractors, government and service providers, businesses, disability rights advocates, and others to find the information that they need to provide accessibility.

For more information about the ADA or the 2010 ADA Standards for Accessible Design call the toll-free ADA Information Line at 800-514-0301 (Voice) or access the ADA website at www.ada.gov.

NATIONAL CENTER OF PHYSICAL ACTIVITY AND DISABILITY (NCPAD) OFFERS FREE MONTHLY ELECTRONIC NEWSLETTER

National Center on Physical Activity and Disability offers a free subscription to a monthly electronic newsletter. To sign up, go to <http://www.ncpad.org/newsletter/>. Topics include information on ADA standards, exercise, tips on weight and nutrition, personal trainers, and pertinent research.

CYBER DISCLOSURE WORKBOOKS FOR YOUTH WITH DISABILITIES & ADULTS SUPPORTING YOUTH WITH DISABILITIES

The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) and the U.S. Department of Labor's Office of Disability Employment Policy has released two supplements to "Cyber Disclosure for Youth with Disabilities."

"The 411 on Disability Disclosure: A Workbook for Youth with Disabilities," helps youth learn about disability disclosure and what it means for them. This document provides youth with suggestions of how to make informed decisions about their own disability disclosure and how to manage their disclosures online. <http://www.ncwd-youth.info/cyber-disclosure>

"The 411 on Disability Disclosure: A Workbook for Families, Educators, Youth Service Professionals, and Adult Allies Who Care About Youth with Disabilities" helps adults make informed decisions about teaching a young man or woman his or her rights and responsibilities in disclosing his or her disability, and how that decision affects a young person's educational, employment, and social life. <http://www.ncwd-youth.info/411-on-disability-disclosure-for-adults>

Search sites like Google, social networking sites like Facebook, and micro-blogging sites like Twitter have added a new element to disclosure. Now it is possible to disclose disability status on the internet without even being aware of it. This can be as simple as a picture of a person using a wheelchair, a comment on a friend's blog about disability, or a profile posted on a disability organizations website.

Excerpted from the National Center on Secondary Education and Transition E-News, found at <http://www.ncset.org/enews/>.

~~~~~

## SBANENY TO HAVE RUNNERS IN THE 2011 NEW YORK CITY MARATHON!

Stay tuned for news about this unique way to raise awareness about Spina Bifida while raising funds to support chapter services.

# SBANENY DEVELOPMENT UPDATE

## SBANENY GOES TO THE THEATER A HIT!

Something very special happened the evening of December 30<sup>th</sup>, 2010!

As you may remember, that evening Spina Bifida Association of Northeastern New York (SBANENY) held a fundraiser at Capital Repertory Theatre in Albany. Those who didn't have the opportunity to attend might ask, "What made the evening so exceptional?"

Our feedback indicates that the details of the evening – great appetizers & desserts, a terrific theater production, and a fun silent auction with something to interest everyone, all provided a great foundation, but the wonder of the evening was beyond that. **The true power of the event came from filling a venue with people who were all supporting a common cause; the mission of SBANENY – to promote the prevention of Spina Bifida and to enhance the lives of all affected.**

**Thank you to everyone from the planning committee, those who made donations of money, goods, and services, our volunteers, and those who attended the event.** The income from the fundraiser is helping to support programs and services provided by SBANENY to individuals and families affected by Spina Bifida in Northeastern New York.

**SBANENY**

**Walk-N-Roll for Spina Bifida 2011**

**Silver Sponsor**

**TIMES UNION**

In Print. Online. All the Time.



for Spina Bifida

## SBANENY WALK-N-ROLL

**Date: April 30, 2011**

**Time: Check In: 9 AM**

**Walk Begins: 10 AM**

**Where: Schenectady County  
Community College  
Schenectady, New York**

**Sign up today** to join us for our Walk-N-Roll for Spina Bifida. Go to [www.firstgiving.com/sbaneny](http://www.firstgiving.com/sbaneny) to register online.... start your team.... sponsor a walker..... There is something for everyone!

**Can't make it to our walk?** No problem! You can still join us as a virtual walker! You can ask your friends to support your efforts to raise funds for the SBANENY. We will still recognize you with all of the walker benefits such as our recognition t-shirts!\*

Offline registration forms are available for those who prefer. Please contact our office if you would like to have a form mailed or emailed to you.

Refreshments.... Community.... Fun....

Prizes!

- Best Team T-shirts
- Team raising the most money
- Team with the widest age range of participants
- Most creative team name
- Team with the biggest family group
- Individual raising the most money
- Individual coming from the greatest distance

**\*Event t-shirts will be provided to all participants who raise \$100 or more for SBANENY Walk-N-Roll 2011.**

**MARCH**

**March 12** Board of Director's Meeting

**APRIL**

**April TBA** Adult's Program  
**April 9** Parent's Program  
**April 30** SBANENY Walk-N-Roll

**MARCH**

**March 12** Board of Director's Meeting

**AUGUST**

**August 28** SBANENY Family Picnic

**OCTOBER**

**October 21 - 23** Spina Bifida Retreat Weekend



123 Saratoga Road  
Scotia, NY 12302

**RETURN SERVICE REQUESTED**

NONPROFIT ORG  
US POSTAGE  
PAID  
SCHENECTADY, NY  
PERMIT NO. 6