



SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK

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SBA of NENY News to Use

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MESSAGE FROM THE CHAPTER CHAIR

Dear SBANENY Friends,

It has been a hot, wet and busy couple of months at the SBANENY office. Hopefully you are all staying cool and dry in the middle of all the heat and rain we have been having. In May, SBANENY held our 3rd Annual Walk-N-Roll for Spina Bifida. This year the Walk-N-Roll was followed by a picnic for all the attendees. Two hundred fifty individuals with SB, families, friends, co-workers, and neighbors joined together for the cause.

Our SB adult group has been busy planning programs and activities. On Saturday, July 13th, a group of adults will enjoy an afternoon together with bowling and pizza. October 12th we will have "Hints for Living Healthy Lives with SB" at the Independent Living Center in Troy. Watch for more details about this event and many others coming soon.

We have been having conversations with parents to get a better understanding of the kinds of programs and activities that will be helpful and work well with busy family schedules. Do you have ideas that you would like to share? Please call or email our office and speak with Karen.

If you have a child with SB who is between the age of 5 and 21, we are having a family retreat weekend at Double H Ranch in Lake Luzerne. Be sure to mark your calendars for October 25 – 27. More information about this event is within this newsletter.

For more information on activities and events, make sure to check our website and like us on Facebook. Do you know of people in NYS who are touched by SB but might not be in contact with our chapter? Please forward a copy of our newsletter to them. Encourage them to sign up. Invite them to attend a SBANENY event with you.

I hope to see you out and about at our events and activities. Remember to stay cool and enjoy the rest of the summer with your family and friends.

Shameka Andrews
Chapter Chair

Disclaimer: *Spina Bifida Association of Northeastern New York 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 informational, educational and entertainment purposes only. It is not intended as medical or professional advice.*

SBANENY NEWS



ADULTS MEET BOWLING & PIZZA PARTY

July 13th, a group of 15+ adults will enjoy some games of bowling, pizza, and good company together. If you are receiving this prior to that and would like to attend, please call Heather at 518-669-9897.

Plans are well underway for a fall program. "Hints for Living Healthy Lives with SB" will be held on Saturday, October 12th at the Independent Living Center of the Hudson Valley in Troy. There will be opportunities to try out Zumba, learn stress reduction techniques, learn some tricks for eating healthy, and enjoy lunch together.

Mark your calendars now. More information will be posted on our website and through Facebook as it becomes available.

HELEN R. MERTENS EDUCATIONAL SCHOLARSHIP FUND

*Sponsored by Spina Bifida Association of
Northeastern New York*

We are pleased to announce that there are two scholarship recipients for the 2013 year.

Congratulations and best wishes to Samantha Campbell and Grady Picinich as they pursue their education and career goals.

Samantha will be attending State University of New York at Delhi this fall, pursuing a degree in liberal arts/social sciences.

Grady is attending State University of New York at Albany, pursuing a degree in Chemistry.

Are you pursuing an educational or training goal?

Applications for 2014 will be available early in January.

SBANENY FALL FAMILY WEEKEND RETREAT AT DOUBLE H RANCH SCHEDULED

Dates & Times: October 25th – 27th, 2013
6 PM Friday evening through Sunday at noon

Where: Double H Ranch, Lake Luzerne, NY

Who: Children with Spina Bifida ages 5 to 21 and their parents/guardians & siblings

What: A weekend of activities designed to help families build and strengthen relationships with others faced with similar challenges.

How: Be prepared – make an appointment for a physical for your child with SB. The required physical forms will be available within the next two months. (If your child is attending Double H this summer, the medical forms required for that will meet the requirements for the fall program.) A physical is required for the qualifying camper (the child with SB). Parents/guardians and siblings will need signed medical waivers.

Registration Forms: Double H tells us that the forms for fall registration will be available shortly. We will send them by email as soon as possible. If you do not have email, please contact our office and we will mail registration forms to you.

Advanced Registration Required:
Deadline for registrations is Friday, October 11, 2013.

Visit Our Website at
www.sbaneny.org

SBANENY EQUIPMENT & SUPPLIES EXCHANGE PROGRAM

The following items are available, first-come, first-serve, for anyone who might be in short supply on a temporary basis.

- ✓ catheters in a variety of styles and sizes
- ✓ Depends underwear for men, size S/M
- ✓ Lidocaine HCl Jelly 2%

Contact the SBANENY office about the items that you need and we will arrange for shipment.

Do you have new, sealed, unused catheters that are no longer of use to you that you would like to add to our supply at our office to be available for others? Contact our office.

Do you have equipment that you are no longer using and would like to pass along to someone who might benefit? Provide us with a description and, if possible, a picture and we will place it in this column.

DISABILITY EMPOWERMENT DAY



Bryan Darby, Pauline Cassillo, and Bobbie Hlat worked together during Disability Empowerment Day at Central Park in Schenectady on June 28th. They helped to raise awareness about SB and inform people about SBANENY services and programs.



SBANENY VOLUNTEER HONORED BY THE NEW YORK AIR NATIONAL GUARD

New York Air National Guard Major Michelle Buonome of Rotterdam Junction has received national recognition from the Northeastern New York Federal Executive Association for her work as a community volunteer. Michelle received the association's Community Service Outside the Agency Award at a ceremony recently. Michelle was honored for her work with the Spina Bifida Association of NENY. She has been a member of the Walk-N-Roll planning committee for 3 years.



Congratulations Michelle and thank you for all that you do for the SB community!

HOW WOULD YOU LIKE TO GET INVOLVED?

- Adult Program Planning Committee
- Young Family Activities & Programs Planning Committee
- Parents of Adults with SB Planning Committee
- Conference 2014 Committee
- Walk-N-Roll 2014 Planning Committee
- Family Picnic 2014 Committee
- Annual Fundraiser Planning Committee
- Volunteer your time and talents

Contact us through Facebook to let us know which projects you are interested in!

Like us on Facebook!

NAVIGATING YOUR HEALTH CARE SPONSORED BY ILCHV

Going to the doctor, or any medically related service, can be overwhelming and confusing to navigate. The Independent Living Center of the Hudson Valley, Inc. is offering a panel discussion to provide self advocating tips. ILCHV will have a variety of professionals to provide education and answer questions.

Date: August 1, 2013

Time: 6:30 – 8:30 PM

Place: ILCHV, 15-17 Third Street, Troy, NY

For more information, call ILCHV at 274-0701.

Light refreshments will be provided.

WHEELCHAIR ACCESSIBLE TAXIS AVAILABLE IN THE CAPITAL REGION



Shameka Andrews checks out one of the new taxicabs CDTA recently added to its fleet to improve accessibility for seniors and people with disabilities. Her picture as well as information about the new program appeared in the Times Union.

- Wheelchair accessible taxis around the Capital Region are available 24 hours/day.
- This program is a supplement to CDTA's STAR (Special Transit Available Request) program. The taxi service offers greater geographic coverage. Rates are the same as for existing taxi services.

Accessible taxi service can be requested by calling the following numbers.

For Capitaland Taxi, call:
Albany County: 456-TAXI
Rensselaer County: 273- 6666
Saratoga County: 583-3131
Schenectady County: 372-7777
Advantage Taxi: 434-3333

SBANENY RECEIVES DONATION BBL FAMILY OF COMPANIES

BBL Family of Companies recently celebrated their 40th Anniversary. They decided to mark the occasion by giving back to the communities where their associates live and work by making donations to charitable organizations nominated by these associates.

Sharon Burlingame nominated Spina Bifida Association of Northeastern New York.

Thank you to Sharon and BBL for your support of programs and services of SBANENY!



Sharon accompanied SBANENY Executive Director Karen Wentworth at a reception on June 11th during which BBL representatives presented a \$1,000 donation check.

SBANENY AWARDED GRANTS BY LOCAL HOLIDAY CAMPAIGNS

Stewart's Holiday Match awarded SBANENY \$1,000.

WGY Christmas Wish, working with partner Curtis Lumber, awarded \$750.

Both grants are funds designated to be used for programs and services for children ages 18 and under.



Walk-N-Roll participants warmed up with Zumba, led by instructor Shannon Riley. Thank you Shannon!

SBANENY CHAPTER CHAIR RECEIVES AWARD

SBANENY Chapter Chair Shameka Andrews was awarded the Beacon Leadership Award from Independent Living Center of the Hudson Valley on May 1st. This award was given in recognition of Shameka's tireless advocacy for people with disabilities. Congratulations Shameka! We at SBANENY know that this award is well-deserved!



SB AWARENESS & EDUCATION PRESENTATIONS

Early this spring, Heather Horwedel traveled south of Albany to present an awareness program to Stephanie Henderson's Girl Scout Troop. If you would like to arrange for an awareness presentation for your school or group, please contact our office. Presentations are adapted to be appropriate for all age groups, children through adults.



Left: Heather devised activities to explain what Spina Bifida is to the Girl Scouts.

Right: Nicholas Henderson shares his experiences about SB with the girls as Heather and parents listen.

ADAPTED LIFE JACKETS

Life Jacket-Adapted is a Canadian company that specializes in flotation devices for individuals of all ages with needs for physical adaptations to enjoy the water. This may be a potential adaptive resource to bring to the attention of your physician or physical therapist. For more information, go to www.pfd-a.com.

NATIONAL PARK SERVICE OFFERS FREE PASSES FOR PEOPLE WITH PERMANENT DISABILITIES

Access Pass permits are available to residents of New York State with permanent disabilities, to enjoy free use of the parks, historic sites, and recreational facilities operated by the New York State Office of Parks, Recreation and Historic Preservation (State Parks) and the New York State Department of Environmental Conservation (DEC) all of which normally contain a charge.

For more information visit the following sites:
<http://www.nysparks.com/admission/access-pass/default.aspx>
<http://www.nps.gov/findapark/passes.htm>

THE FASTEST WAY TO VERIFY SOCIAL SECURITY & SSI BENEFITS

If you are in need of proof of Social Security or Supplemental Security Income benefits, you can get a benefit verification letter online instantly through **my Social Security** account.

With **my Social Security** you can view, print, or save an official letter that includes proof of your:

- Benefit amount and type;
- Medicare start date and withholding amount; and
- Age.

Go to www.socialsecurity.gov/myaccount for step-by-step instructions about how to create an online account, and an explanation about how to get a benefit verification letter.

RESOURCES ABOUT THE AFFORDABLE CARE ACT (ACA)

NYMAC (New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services) has resources on their website that address a variety of issues related to the ACA:

- For Providers - How will the ACA affect your patients? Your practice? etc.
- For Patients and Families - Will your state ACA programs cover your needs and help you get insurance?
- For Public Health Professionals - Does the ACA address the needs of your populations?

For more information, go to www.wadsworth.org/newborn/nymac/aca.htm.

RESEARCH STUDY: SIBLINGS OF PEOPLE WITH DISABILITIES PARTICIPANTS NEEDED

Do you have a brother or sister with an intellectual or developmental disability?

Are you 18 years and older and live in the US?

Do you provide care and/or support to your brother or sister with a disability? This can include everything from living with your sibling to driving them to the doctor, to talking on the phone and visiting.

If so, you can participate in an hour long online survey that looks at empowerment, thoughts and beliefs, and mood among adult siblings of individuals with intellectual and developmental disabilities. Your participation can help in understanding needs of adult siblings who provide any form of care and support to their brothers or sisters with intellectual disabilities. Four lucky winners will receive \$50 Sears gift cards.

This research is conducted under the direction of Dr. Anne F. Farrell, HDFS, University of Connecticut. If you need additional information about the study, contact her at anne.farrell@uconn.edu. Survey Link - <https://www.surveymonkey.com/s/siblingcaregivers>

NEUROGENIC DETRUSOR OVERACTIVITY (NDO) DISTRESSING YOUR CHILD?

- Does your child experience daytime wetting and need to make urgent trips to the toilet?
- Is he/she aged between 5 and 17 years and have confirmed NDO?

Then your child may be able to take part in MONKEY, a clinical research study investigating whether an existing medicine for overactive bladder (OAB) in adults is also safe and effective for NDO. If you would like more information, please contact the study team:

The Urological Institute of Northeastern NY
518-262-8579

SURVEY FOR PERSONS AGES 15 TO 24 WITH SPINA BIFIDA

The Department of Family & Preventive Medicine, School of Medicine, University of South Carolina, is looking for 15 to 24 year-olds who have Spina Bifida, Muscular Dystrophy or Fragile X Syndrome who are willing to tell about their school, work, family, and community life, in an online survey.

The University is operating under Centers for Disease Control and Prevention (CDC) financial assistance and guidance. The American Association on Health and Disability (AAHD) is a partner on this CDC USC project. USC plans to use this information to provide concrete recommendations to policy makers who can effect change in the provision of essential services needed by adolescents as they transition into adulthood.

USC needs at least 600 people to complete the survey by June 30, 2014 in order to provide the most accurate recommendations to policy makers. So far, 153 people have completed the survey. If USC is going to achieve the CDC goal, they need your help!

To participate in the survey, go to www.surveymonkey.com/s/hwbssnational.

Questions? Please contact Margaret Holland at (803) 434-2365 or at Margaret.Holland@uscmcd.sc.edu.

BUILDING NETWORKS FOR A “GOOD LIFE,” EVEN AFTER THE CAREGIVER IS GONE

This article in the New York Times touches on concerns often shared by caregivers about the future. It addresses questions such as, “What will happen to my loved one after I am no longer able to manage his/her care? How can I ensure that this responsibility is covered even after I am gone? How do I develop the social support networks that will be needed?”

To read the complete article, go to:

http://opinionator.blogs.nytimes.com/2013/06/26/in-networks-for-people-with-disabilities-a-good-life-is-the-goal/?_r=0

NATIONAL SPINA BIFIDA ASSOCIATION 2013 EDUCATION DAYS BALTIMORE, JUNE 1, 2013

During an education day sponsored by national SBA on June 1st, Karen Wentworth, SBANENY Executive Director attended a variety of workshops. She will be sharing information from the sessions she attended over the next few months.

Helpful Apps, presented by Andy Zabel, Ph.D., ABPP & Shruti Rane, Ph.D.

Apps can be used as accommodations for nonverbal learning disabilities. The following are Apps available for Androids and Apple products that can be useful tools.

Educreations: A recordable interactive whiteboard that can be used to create video lessons. This can be a helpful tool to make how-to videos for self-care and household activities to increase independence in these and other areas.

Math Apps

- **Freefall Math:** Offers a fun option to practice math from basic math facts to higher level math skills.
- **Math Racer:** Designed to improve math fluency.
- **Hungry Fish:** Practice mental addition & subtraction while feeding the fish
- **Freefall Money or Coin Math:** Helps to develop skills for adding money and making change. Can be used for grocery shopping to give you a total spent as you go.
- **Coin Calculator:** Teaches math skills for daily life

Finances Apps

- **Mint.com:** This app gives a complete portfolio of finances at a glance. This can be used to help an individual plan and organize his/her finances. It helps to categorize spending trends and gives alerts for paying bills. It can be used to set up a budget. This cannot be used to move money between accounts. Some banks offer a similar service.

Reading, Spelling, & Writing

- **WordQ:** Text-to-speech, helps the user to spell words. This highlights text while reading it to you. It can help adults to gain independence.
- **Dragon Dictation:** Can be used to dictate written reminders.
- **Sky Wifi Smartpen:** Helps with note taking. Allows the user to note places that are important in a lecture and return to those notes.
- **Perfect Notes:** Gives an audio recording of a lecture. The user can mark points in the lecture to easily return to for review.
- **Livescribe:** The pen records text and voice digitally as you write on paper
- **Sketch:** Free iPad/Android app that allows you to sketch, annotate figures, photos, & diagrams.

MS. WHEELCHAIR AMERICA SEEKS APPLICANTS

The mission of **Ms. Wheelchair America** is to provide an opportunity of achievement for women who happen to be wheelchair users to successfully educate and advocate for the more than 54 million Americans living with disabilities. Unlike traditional beauty pageants, Ms. Wheelchair America is not a contest to select the most attractive individual. It is instead a competition based on advocacy, achievement, communication and presentation to select the most accomplished and articulate spokeswoman for persons with disabilities.

To compete you must be a woman between the ages of 21 and 60 who uses a wheelchair 100% for daily mobility. The selected representative must be able to communicate both the needs and the accomplishments of her constituency to the general public, the business community and the legislature.

For additional qualifications and information regarding the competition, contact Shameka Andrews at mwny2006@yahoo.com.

The next competition is being held August 10th at the Independent Living Center of Hudson Valley.

WEBINARS FOR PARENTS

Parent to Parent of NYS is a resource for families of individuals with special needs and the professionals who serve them, offering opportunities to meet and share information.

The following are free webinars being offered this summer.

- o Grief, Loss, and Adjustment for Parents of Children with Special Needs, July 9th
- o Education Records Organizer, July 16th
- o A Parent's Guide to Special Education, July 17th
- o MSC for Families: Getting the Most Out of Your Child's Program, July 29th
- o What is Section 504?, August 5th
- o A Guide for Families to Understanding Supports & Services Administered by OPWDD (Office of Persons with Developmental Disabilities), August 14th
- o Preventing Parent Burnout for Parents of Children with Special Needs, August 20th

For more information, go to:

<http://www.parenttoparentnys.org/news/statewide-events/>

JAMBOXX:

DEVICE AIDS CREATIVE EXPRESSION

Jamboxx is a device that lets people with disabilities create music using controlled breathing. This harmonica-like device, designed locally, attaches to a computer. People with limited mobility are able to create music through sipping and puffing motions. Players are able to create musical notes on a variety of digitized instruments. The Jamboxx allows for creative outlets. In addition, it can also provide physical benefits, improving lung capacity for people who have limited physical activity.

The Arts Center of the Capital Region in Troy will be offering mobility-impaired students class options that will include the use of Jamboxx.

To learn more, see the article in the Times Union that appeared recently:

<http://www.timesunion.com/local/article/A-device-to-aid-creative-expression-4577417.php>

NATIONAL COLLABORATIVE ON WORKFORCE AND DISABILITY (NCWD)/YOUTH RELEASES YOUTH IN ACTION!

TIP SHEETS FOR YOUNG PEOPLE

There are a variety of actions that youth can take to promote their personal growth and develop personal and leadership skills needed in today's workplace.

In conjunction with the Office of Disability Employment Policy at the U.S. Department of Labor, NCWD/Youth has developed a series of Youth in Action! Tip Sheets identifying some activities that can help youth learn and think about important transition issues including: Becoming a Stronger Self-Advocate; Leading Your Transition Planning; Learning Disability History; Getting Involved in Volunteering; Serving on Decision-Making Boards; and Participating in Internships and Work-Based Experiences.

While these tip sheets are designed for youth to read and use, they are also helpful tools for family members, educators, and youth service professionals to use in discussions with youth.!

To view all of the Youth in Action! Tip Sheets, please visit: <http://www.ncwd-youth.info/youth-development>



In addition to our many sponsors, SBANENY received generous donations from a variety of local businesses including Hannaford Supermarket, Manhattan Bistro & Bagel of Scotia, Stewarts Shops.

SBANENY DEVELOPMENT UPDATE



SBANENY Walk-N-Roll for Spina Bifida 2013

Presented by

THE
GAZETTE



The combined efforts of over 20 volunteers, 250 participants, 28 teams, 30 businesses, and over 500 donors, raised over \$32,000 to support the programs and services provided by SBANENY. Congratulations to all for a job very well done!



SBANENY Walk-N-Roll for Spina Bifida was a color filled day, with blue sky, sunshine, and a rainbow of t-shirts!



*Thank you to our new friends from
Macy's Rotterdam and MVP!*



Volunteering... It's rewarding and fun!

Congratulations to this year's award winners...



*Individual raising the most money,
Nicholas Henderson with his siblings*



*Team Raising the Most Money,
Team Jilly Bean*



*Most Creative Team Name,
The Place Beyond the Wheels*



*Most Creative Team T-Shirt,
Awareness for Aly*



*Last, but not least! Thank you to Walk-N-Roll
2013 committee, joined by Congressman Paul
Tonko & DJ Brother Lou Roberts, for all of
their efforts that made this a successful event!*

Thank you to our sponsors!

THE
GAZETTE

MOBILITYWORKS
Home ADAPTIVE VEHICLES
MAKING THE WORLD ACCESSIBLE



*Special thanks to Kaelco Photography --
Karin Tirinato for capturing our day in
these and many more great pictures!*

180 Medical Uromed
T.M. Byxbee Co. CPAs Pepsico
Schenectady Insuring Agency
Lydia Rollins & Rich Rollins
of Morgan & Stanley Wealth Management

Dare to Dream With



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

Fundraising Event!

Join us for

***“The Singing Anchors” Holiday Show
with Benita Zahn, Jessica Layton, & Jerry Gretzinger
as originally produced at the
Fort Salem Theater, Salem, NY***

A night of music and more....

December 7th at 6:30 PM

❖ Appetizers & Desserts

❖ Silent Auction

**SIVERhills Restaurant and Banquet House
*at Pinehaven Country Club***

Just a Tease or Two about our December Auction.....

What's on your list?

- * Perhaps a trip or two...
- * the perfect present for the one who has everything...
- * a gift for the nature lover...
- * a book, fine food, some vino...
- * a night out on the town...
- * a vineyard tour...
- * a sparkling gem...

Ticket information will be available this fall.

**See our website www.sbaneny.org
or like us on Facebook for updates!
admin@sbaneny.org 518-399-9151**



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SBANENY CALENDAR OF EVENTS

OCTOBER

October 12

October 25 – 27 Adults – Hints for Living Healthy Lives with SB
Retreat Weekend
for Families with Children with SB ages 5 to 21

DECEMBER

December 7

2014

SBANENY Dare to Dream Fundraiser with SBANENY
SBANENY sponsored conference TBA
SBANENY Walk-N-Roll for Spina Bifida 2014 TBA

WATCH FOR FLYERS,
FACEBOOK UPDATES,
EMAILS, AND OUR
WEBSITE FOR
INFORMATION ABOUT
ADDITIONAL EVENTS
AS THEY GET PLANNED.

SBANENY BOARD MEETINGS July 13, September 14, November 9, 2013

Estate Planning, Memorials & Honorariums

Have you considered including SBANENY in your estate plans? You may also want to consider honoring or memorializing a friend or a loved one with a gift to SBANENY.

For more information, contact Karen at 518-399-9151 or admin@sbaneny.org.