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MESSAGE FROM THE CHAPTER CHAIR

For the last few months the SBANENY office has been buzzing with volunteers preparing for our 3rd Annual Walk-N-Roll for Spina Bifida and SBANENY Family Picnic on May 4th at Schenectady's Central Park. We are expecting a great crowd of people from all over New York State to come together to enjoy this event.

Our Adult Activities Planning Committee has a lot of great ideas for activities and programs for adults. If you would like to be a part of the committee or just have ideas for us, please call the office. All ideas are greatly appreciated. Our first event was a conversation and dinner event with neurosurgeon Dr. Matt Adamo. The planning committee will meet again in June to discuss summer and fall activities.

I want to thank all of the members of these committees for taking time out of their busy schedules to help plan these great events. We would not be able to do it without you. There are many ways to volunteer your time for our events and activities. We are always looking for volunteers, to be members of the board, chair and be members of committees, help with mailings, or volunteer at one of our events. We love having new faces and new ideas.

I also invite you to check us out on Facebook and share your photos and experiences from our events. We love to see the photos of people that have attended our events posted on our Facebook page. If you have ideas on how we can improve the page, please feel free to share those as well. We want to have a page that people enjoy.

See inside for more information about future activities. Please save the date for our annual fundraiser on December 7th. We are beginning to plan a spring 2014 conference. Consider joining the planning committee.

I hope to see a lot of you and your families at these events.

Shameka Andrews
Chapter Chair

SBANENY

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SBANENY NEWS

SBANENY FAMILY PICNIC MAY 4TH 11:30 AM TO 2:30 PM

SBANENY is hosting a family picnic immediately following our Walk-N-Roll for Spina Bifida.

Date: May 4, 2013

Time: 11:30 AM to 2:30 PM immediately following the Walk-N-Roll

Place: Large Pavilion, Central Park, Schenectady

What: Picnic food, activities and games

Fee: There is no fee for the picnic.

RSVP: *If you plan to attend the picnic but are unable to be at the walk, please contact our office in advance. We want to be sure we have enough food for everyone!*

What Can You Bring? Please bring an activity or game to share with others.

ADULTS MEET CONVERSATIONS & DINNER WITH DR. MATTHEW ADAMO

On April 17th a dozen adults with Spina Bifida and some family members met for dinner and a conversation with Dr. Matthew Adamo. Dr. Adamo is a neurosurgeon at Albany Medical Center and has expertise in serving both children and adults with Spina Bifida. The program was sponsored by the Adult Committee of SBANENY based upon feedback we received from adults with Spina Bifida who wanted the opportunity to learn



more about Spina Bifida and what to expect as we age.

We gained a better understanding of many of the terms we have heard our entire lives, such as Chiari Malformation, tethered cord, and myelomeningocele. We also learned ways to maintain function we have and what kind of specialty care we need to ensure healthy living. This proved to be a great way to find out information in a relaxed environment, and also to connect with other adults, who shared their own suggestions for what works.



The Adult Committee will be sponsoring programs on a quarterly schedule. If you have ideas about what type of programming you would like and/or suggested speakers, call Karen at the office.

Visit Our Website at
www.sbaneny.org



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 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: Forms will be emailed as soon as they are available. (They are anticipated at the beginning of the summer.) 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.

PROGRAM PLANNING COMMITTEES PARTICIPANTS NEEDED

Based upon feedback from the Spina Bifida community, our board has set a goal to expand upon the group services that we offer. We now have an active committee of adults planning programs for that constituent group. Two additional groups that have been identified with a need and interest are

- families with children with SB under 21 and
- parents of with adults with Spina Bifida.

We need your input and welcome your participation. The best way that we will know what is needed and works is to have input in the planning stages from representatives of these groups. Would you be willing to serve on a committee for program planning that meets (in person or by conference call) 2 or 3 times a year?

We would like to start these committees before summer begins. *Please call our office today if you are interested.*

SCHOLARSHIP OPPORTUNITIES

HELEN R. MERTENS EDUCATIONAL SCHOLARSHIP FUND

*Sponsored by Spina Bifida Association of
Northeastern New York*

Are you pursuing an educational or training goal?

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. For further information & applications go to our chapter website at www.sbaneny.org or contact our office.

Applications will be accepted through April 30, 2013.

SBANENY EQUIPMENT EXCHANGE PROGRAM

- **Hand powered tricycle** -- It's is spring – time to get out and ride our bikes! One of our families has a hand powered tricycle that they would like to pass along to another child. Their son has outgrown it. The bike is for a preschool age child. If you are interested in this for your child, please contact our office.
- **Hospital Bed** – There is a hospital bed available. Please call the office for more information.



Among many others, Heather & Pauline added to our fun with the mailing project!

CATHETER SUPPLIES

Our office has a supply of catheters in a variety of styles and sizes. These are available for people who might be in short supply on a temporary basis. If you are in need, please contact our office for more information.

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.

VOLUNTEERS SAVE THE DAY!

Periodically large mailings go out of our office. We are very fortunate to have teams of volunteers to help with these projects! Thank you to all who helped with our large mailing for this year's Walk-N-Roll and Family Picnic. For a week, we had people coming and going. Some worked at the office, others brought bins of flyers home to fold and sticker with family. Our interns at Scotia-Glenville High School's Life Skills Classroom worked in their classroom. It was truly a case of "many hands make light work!"

NICK, HIS FAMILY & HIS COMMUNITY WALK & ROLL FOR SPINA BIFIDA

On Sunday, April 21st at Copake Park, over 150 friends, family and community members came out to support 'Nick's Walk 'n Roll 2013'.

The event organizers were Stephanie and Darrel Henderson. Their son Nicholas, who attends the first grade at Taconic Hills Elementary School, was born with Spina Bifida. This event has been named after him. Among those in attendance were the



Nick shows an SB awareness button made for participants in the walk.

Girl Scout troops and Cub Scout pack 130 from Columbia County. Stephanie says it's all about raising awareness of Spina Bifida.

The Hendersons are participants in the annual Walk-N-Roll for Spina Bifida sponsored by our chapter. They felt the need to raise awareness in their own community and so started their own event several years ago. The family has found the support from businesses in their area remarkable. The family successfully raised over \$2,000 at the event and another \$1500 on line at Nick's website for the Walk-N-Roll here in Schenectady on May 4th.

If you have any questions or if you would like more information about how to raise awareness in your community, please contact Karen at admin@sbaneny.org or call 518-399-9151.

Thank you Stephanie, Darrel, Nick and the entire Henderson Family!

VOLUNTEER RAISES SB AWARENESS

In the fall of 2012, volunteer Linda Ciano had an idea about what she might be able to do to help the SB cause. After discussing her plan with our office, she started in on her project. Six months later, she has reached out to hundreds of businesses and individuals requesting donations for the silent auction that will be held during the SBANENY Annual Fundraiser on December 7th. Because of her efforts, we are well on our way to having another great silent auction.

Little did she know when she started her project the real impact that her research and requests were going to have. Each email, letter, and phone call that she has made has educated another person about Spina Bifida and the individuals and families served by SBANENY. Thank you Linda!

Like us on Facebook!



Linda carves a pumpkin with her daughter Zoe during the 2012 family weekend at Frost Valley.

DO YOU HAVE A KOHL'S CONNECTION?

Kohl's Cares is a great program that other chapters are finding very helpful. They encourage associates to volunteer to help nonprofits. When their associates show a level of interest in a program, Kohl's also will donate \$500.

Do you know someone who works for Kohl's? Here is how you can help. Work with us to encourage volunteers from Kohl's to help with our next projects; preparing a large mailing in July or volunteering at the annual fundraiser. SBANENY has the potential to benefit in two ways; great volunteers & \$500 donations from Kohls.

If you have a Kohl's connection, please call the office as soon as possible. Thank you.

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
- Annual Fundraiser Planning Committee
- Volunteer your time and talents

Call & talk with us about what you would like to do!

INDEPENDENT LIVING CENTER OF THE HUDSON VALLEY INTRODUCES CHAIR YOGA PROGRAM

The Independent Living Center of the Hudson Valley is introducing a new program for Chair Yoga.

When: Every Thursday, 1:15 to 2:15 PM

Instructor: Loretta Pyles, Certified Yoga Instructor

Location: Independent Living Center of the Hudson Valley, 15 - 17 Third St., Troy

What: The yoga class is open to the public and is perfect for someone just starting, or with mobility impairments, in a safe, comfortable environment. The class is open – you can join anytime and attend without prior registration.

Fee: Minimum donation of \$1 to participate

Questions? See attached flyer.
Call Tara Kavanaugh at 518-274-0701

Note: Young Women's Support Group (under 40) takes place immediately following yoga every other week. Take yoga and then stay for the group! See below for support group details....

What? Women's Support Groups

Where? ILCHV's conference room, 15- 17 3rd Street, Troy

Who? Ages 18 -40: **When?** Every other Thursday from 1:00pm to 2:30pm

Who? Ages 40 and over: **When?** Every other Tuesday from 11:00am- 12:30pm

Why? Come join a support group for women with disabilities and those women who are

caretakers for individuals with disabilities. Also enjoy fun activities with the group.

Walk-Ins Are Welcome! Stop by or call Tara at 274- 0701 ext. 126 for more information!

NATIONAL SPINA BIFIDA ASSOCIATION 2013 EDUCATION DAYS: SETTING THE COURSE FOR TOMORROW

Education days are being sponsored by national Spina Bifida Association. Below is information about the event that will be held closest to NYS.

Location: Baltimore, Maryland Agenda
Date: June 1, 2013, 9 AM to 5 PM

Topics include:

- Learning and School
- Secondary Conditions in Spina Bifida
- Health Issues in Adults with Spina Bifida & Getting the Care You Need
- Helpful Apps
- Chiari & Hydrocephalus
- Tethered Cord: What to tell the doctor?
- Bladder & Bowel Management
- Non-surgical Management of the Bowel
- Maximizing Ambulatory Potential in SB
- Therapy & Adaptive Equipment for People with SB
- Endocrine Issues in People with SB
- Behavioral Health & Transition
- Maintaining Your Health with Exercise, Adaptive Sports, & Healthy Eating

For more information, please go http://www.spinabifidaassociation.org/site/c.evKRI70X1oJ8H/b.8383237/k.7DC4/Education_Days.htm.



SBANENY
Email Address Change
Please note:
admin@sbaneny.org.

SBANENY DEVELOPMENT UPDATE



SBANENY Walk-N-Roll for Spina Bifida 2013

Presented by

THE
GAZETTE

Are you registered yet? Do you have a team? As of this writing, we have 21 teams registered, including almost 90 people. That's almost twice as many as we had last year at this point!

This promises to be a great day. The morning will begin with bagels and coffee during registration. After we all get in a walk/roll around the beautiful lake, we will be enjoying a family picnic complete with ice cream!

What do you need to do to participate? To register, go to www.sbaneny.org and click on the logo:



You can also register offline. Contact us for a registration form.

We also welcome walk-ins the day of the event!

Contact our office today to sign up!

SBANENY Annual Fundraiser

Date: Saturday, December 7, 2013

Time: Evening – details to follow

Place: Siverhills Restaurant & Banquet House

Entertainment: The Singing Anchors Benita Zahn & Jessica Layton of Channel 13 news, Jerry Gretzinger of Channel 6 news will take to the stage and entertain us with a fantastic evening of song and banter. To learn more about the group, go to <http://thesinginganchors.weebly.com/>.

The event will include a silent auction, and appetizers by J & J Ruggiero's Catering.

The silent auction will be previewed online prior to the event. Watch for further details.

In the meantime, you will want to mark your calendars today for this fun event!

ACCESSIBLE CRUISING WITH A DISABILITY

ADULTS WITH SB TAKE A CRUISE

Michell Haase Huber is the parent of a young adult with Spina Bifida. She started TravelinWheels two years ago to assist people with disabilities to travel the world on their own terms and with confidence. Primarily, she builds city accessibility guides, but she had a goal to do something that would be a direct opportunity for the Spina Bifida community. With a belief that travel is one of the best ways for people to learn about themselves, she planned a cruise.

To read more about the trip, go to http://www.travelinwheels.com/travelstories/story_story.aspx?which=active&uid=421 http://www.travelinwheels.com/travelstories/story_story.aspx?which=active&uid=421 The next trip is planned for March of 2014.



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SBANENY CALENDAR OF EVENTS

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

MAY

May 4

SBANENY Walk-N-Roll for Spina Bifida
Presented by the Daily Gazette &
SBANENY Family Picnic

OCTOBER

October 25 – 27 **Retreat** Weekend for Families with Children with SB ages 5 to 21

DECEMBER

December 7 SBANENY Annual Fundraiser, The Singing Anchors, Silent Auction

SPRING 2014 SBANENY sponsored conference

SBANENY BOARD MEETINGS May 6, 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.