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MESSAGE FROM THE CHAPTER CHAIR

Dear SBANENY Friends,

I can't believe it's the beginning of a new year. To close out 2013 and celebrate our 20th anniversary, we had our annual fundraiser and silent auction event in December at the Siver Hills Country Club in Guilderland. We honored those people who founded SBANENY for their vision and commitment to the organization in the early days. Entertainment was by The Singing Anchors and hors d'oeuvres catered by Ruggerios. I want to thank Debb Rosemarino, Linda Ciano, Kevin Chamberlain and Karen Wentworth for putting together a fabulous silent auction and event.

We also said goodbye to board member Dan O'Connell. We would like to thank him for his service and commitment. We hope that he will continue to participate in future chapter events. We welcome new board members Michelle Miller and Lyndsi Holmes. If you or anyone you know would like to serve on the board, any of our committees, or volunteer in some other capacity please contact our office at 518-399-9151 or at admin@sbaneny.org.

I would like to thank all of our volunteers and staff for their commitment. Together we are ensuring the sustainability of this organization and the services that are provided to individuals and families affected by Spina Bifida.

In the coming year, we will continue to reach out to more individuals and families affected by Spina Bifida. Our committees are working hard to provide great programs and events for the upcoming year. See inside this newsletter, visit our website, follow our Facebook page, and watch for emails to stay current with SBANENY programs and events!

I hope this coming year brings you and your family many blessings.

**Shameka Andrews
Chapter Chair**

SBANENY

Board of Directors

- Shameka Andrews, Chair
- James Dunham, Vice Chair
- Stephanie Mumford, Treasurer
- Vacant, Secretary
- Kevin Chamberlain, Past Chair
- Amy Clinton
- Barbara Devore
- Raymond Langelier
- Dr. Matthew Adamo
- Michelle Miller
- Lyndsi Holmes

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 TO MEET FOR A WORKSHOP ON BUILDING HEALTHY RELATIONSHIPS

Who: Adults with Spina Bifida

When: Saturday, January 18, 2014

Time: 1 to 3 PM

Where: Colonie Town Library, conference room

Topics Include:

- o Online Dating
- o Personal Assistance
- o Ups & Downs challenges
- o When & How to Talk About Your Disability
- o Benefits

Please RSVP to Shameka at 432-3202 or to our office.

Are you interested in participating in our adult program planning committee? Contact our office for information.

NEW YORK CITY AREA PROGRAM IN PLANNING STAGES

Are you located in New York City or surrounding areas? We are facilitating a meeting of people living with Spina Bifida in the NYC metropolitan area and would love to hear from you! We are planning the event in early spring and expect to have details available very soon. If you are interested in being a participating in activities in that area, please contact Rachael at rachael.strohl@sbaneny.org or 399-9151. In the meantime, watch for information and details.

MIDDLE ADULTS LUNCHEON

Are you around 40 or older, and living with Spina Bifida? Would you like to talk to your peers?

SBANENY is sponsoring an informal luncheon for 40ish or older individuals. It will take place on Feb 22nd from 12 to 2 at our office. Please RSVP to Barbara Devore at 439-8423 or barbaradevore1@gmail.com by February 19th.

SCHOLARSHIP OPPORTUNITIES

FRANK BUCINO JR. MEMORIAL SCHOLARSHIP

Spina Bifida Association of Northeastern New York (SBANENY) has established the Frank Bucino, Jr. Memorial Scholarship in cooperation with Frank's family. The purpose of the scholarship is to award financial assistance to support;



1. **Conference Scholarship:** Individuals who have Spina Bifida and their immediate family's attendance at a national or regional Spina Bifida conference. The goal of the Conference Scholarship is to encourage individuals and families to attend the SBA Conference or Education Day, or an SBANENY sponsored conference. These events provide a great opportunity to meet others living with Spina Bifida; learn more about living with Spina Bifida, make friends and enjoy seeing old friends; share tips and tricks; learn the latest medical information from doctors and other experts; and have an amazing experience overall!

OR

2. **Educational Scholarship:** Individuals with Spina Bifida who are pursuing education or technical training.

Information, guidelines, and applications are available on our website at www.sbaneny.org.

HELEN R. MERTENS EDUCATIONAL SCHOLARSHIP

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.

The deadline for receiving applications and
all supporting materials is May 1, 2014.



SBANENY FAMILY & FRIENDS PICNIC

DATE: Saturday, May 17th

PLACE: Central Park, Schenectady, NY

TIME: Immediately following the Walk-N-Roll

WHO: Participants of the Walk-N-Roll

FEE: There is no charge to participate.

Come and join in the fun!

Volunteers are needed! Help to plan the food
and organize the picnic. It's a rewarding event
with lots of participants! Please contact Karen at
our office today and let her know what you can
do to help out with this.

Like us on Facebook!

SBANENY EQUIPMENT & SUPPLIES EXCHANGE PROGRAM

The following items are available through our
equipment exchange program. Please
contact our office if there is an item of
interest.

- Good condition, used child's wheelchair.
Dark purple. Wheels are removable, back
flips down for storage/transport. Contact
our office if you are interested.

The following items are available, 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%
- ✓ Depends

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

SCHENECTADY CITY COUNCIL HELPS TO RAISE AWARENESS FOR SPINA BIFIDA

*Schenectady City Council presented representatives
of SBANENY with a resolution recognizing October as
Spina Bifida Awareness
Month. The lights on one
side of Schenectady City
Hall were teal for the
month.*



SBANENY NEWS

A LOOK BACK AT 2013...

DOUBLE H RANCH

Our Fall Family Weekend at the Double H Ranch was a huge success. With 20 families in attendance we were able to embrace the excitement and joy that Double H brings to children's lives.

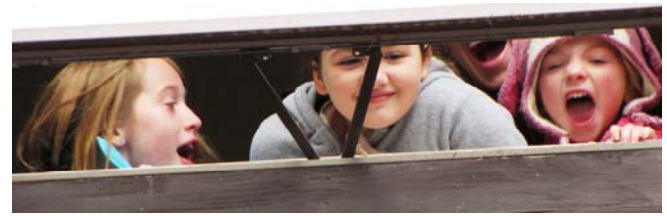
Our weekend was filled with....



... group gatherings, singing camp songs, led by Jason, Mikala, and Double H staff.



Looking ahead to 2014...
Mark your calendars!
Fall Family Weekend 2014
will be October 24 – 26.



.... enjoying new perspectives...



.... working hard to explore new heights...



.... enjoying the moment!



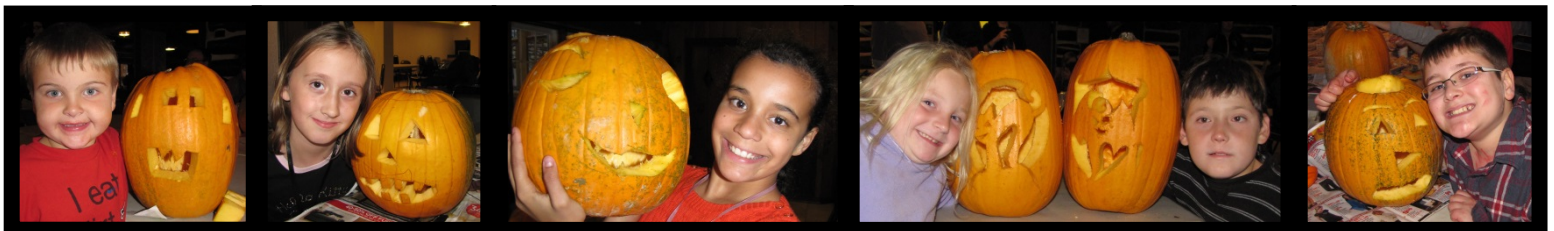
.... focusing on the goal ...



.... treasured moments with loved ones ...



.... costume parties ...



... and pumpkin carving, a favorite activity and tradition!

WHAT PEOPLE WITH SPINA BIFIDA NEED TO KNOW ABOUT FOLIC ACID

January 5 – 11, 2014 is Folic Acid Awareness week. Because Spina Bifida occurs within the first month of fetal development, it is important to begin taking folic acid before you get pregnant. According to the Centers for Disease Control, 50% of pregnancies are unplanned; they therefore recommend all women of childbearing age take 400 mcg (0.4 mg) of folic acid every day.

For women who have had a history of a pregnancy affected by Spina Bifida or who herself has Spina Bifida, she may, in consultation with her doctor, be prescribed a higher dosage of folic acid (4000 mcg or 4.0 mg.) This amount of folic acid is higher than what you can get in an over the counter vitamin, so you will need to talk to your health care provider for a prescription.

Folic acid is a B vitamin and occurs naturally in many fruits and vegetables. It is also in certain cereals and grains. However, the Spina Bifida Association of America notes that although diet with a lot of folic acid is good for you, most people do not get enough through food alone. They suggest the best way to get the right amount is to take a vitamin with folic acid every day.

As with all health issues, to determine what is right for you, start a conversation with your health care provider. He/she can guide you in the direction of taking care of yourself and if you decide, your future baby too!

TRANSITION PLANNING

Are you or your child reaching the middle to end of their teen years? It is time to start planning for the next stage of life – adulthood!

When planning for adulthood, there are 4 key things to consider.

1. Vocational Goals: A great place to start is Adult Career and Continuing Education

Services-Vocational Rehabilitation (ACCES-VR). ACCES-VR offers access to a full range of employment and independent living services that may be needed by persons with disabilities through their lives.

- 2. Education:** Considering college? Two and four year colleges offer a resource center for individuals with disabilities, which can assist in providing accommodations for students. Thinkcollege.net provides a full listing of transition programs for individuals with learning disabilities.
- 3. Health Care:** A successful health care transition requires sensitivity, cooperation and commitment of a transition team comprised of the teen, parents, pediatricians and new providers of adult health care. The team should identify adult health care providers who are willing to accept the primary health care role while integrating both adult and pediatric providers in the first few months during the transition. Teens should adopt and maintain the role of care coordinators, maintaining their own health care records. However, understanding one's own limitations and knowing when to ask for help are part of the transition process.
- 4. Living arrangements:** Teens should be encouraged to develop decision-making skills that relate to community living-from daily activities like grooming, cooking and housekeeping to more complex skills like managing finances and acquiring agency services. ACCES-VR is a resource to consider when planning for you or your child's future living arrangements.

Visit Our Website at
www.sbaneny.org

SBANENY NEWS

RECREATIONAL IDEAS IN THE AREA

Several organizations in or near the Capital District offer activities for youth and adults throughout the year.

STRIDE (www.stride.org)

SAFE (www.sportsareforeveryone.org)

Double H (www.doublehbranch.org)

Fast Break (<http://www.fastbreakfund.org/>)

Upcoming Events:

January: STRIDE Skiing! Sled Hockey!

<http://www.stride.org/>

January 6: Double H Summer Camp

Registrations are available

<http://www.doublehbranch.org/summer-camp/criteria/>.

Mid January: STRIDE Swim & Target Shooting Begin

January 17: STRIDE Dance Class Begins

March 1: SAFE Bowling Begins

April 5, 12, 19: SAFE Fishing

Spring: Fast Break Baseball

April 26: SAFE Baseball Begins

Early May: STRIDE Golf Begins

July & August: Fast Break Basketball Camps

GRANT OPPORTUNITIES

Are you looking for financial grants and scholarships for education, training, home modifications, or assistive technology or other needs? Our office receives many calls with these questions. Below are some of the resources that you might want to contact:

Gabe's Hope: Provides assistance for a variety of things, including college scholarships, home modification and assistive technology.

<http://www.gabeshope.org/resources/scholarships/>

Aubrey Rose Foundation: Applications reviewed quarterly, next in March

<http://www.aubreyrose.org/grants>

Challenged America: Equipment Purchases

<http://challengedamerica.com/tell.asp?page=3>

Children's Charity Fund: Mainly medical equipment and educational grants

<http://www.childrenscharityfund.org/grants.html>

Disabled Children's Relief Fund: Assistive devices, rehabilitative services, arts and

humanities projects; Application opens in April
<http://www.dcrf.com/orderze/Content/1/Summary.aspx>

Different Needz Foundation: Medical services and equipment; Deadline is March 1
<http://www.differentneedzfoundation.org/grants/>

First Hand Foundation: Treatment, equipment, vehicle modifications and dislocation expenses.
https://applications.cerner.com/firsthand/FirstHand_1a.aspx?id=28729

Gia Foundation: Purchases specific item(s) to assist daily functioning
<http://www.giafoundation.com/extensions>

Parkers Purpose: Provides assistance to families in an immediate financial crisis
<http://parkerspurpose.net/index.php?page=application-for-assistance>

Wheel to Walk: Medical equipment not covered by insurance
http://www.wheeltowalk.com/index_application.htm

ChairScholar Foundation Medical equipment not covered by insurance: Available to high school seniors and college freshmen who use wheelchairs for mobility and are under 21. National and New York Metropolitan Area scholarships available.
<http://chairscholars.org/>

AmeriGlide Achiever Scholarship: Available to college students who have finished at least one year of college and use a manual or electric wheelchair.

<http://www.ameriglide.com/Scholarship/>

American Association on Health & Disability: Available to undergraduate and graduate students with a disability. Preference given to students majoring in public health, disability studies, health promotion or a field related to disability and health.

<http://www.aahd.us/initiatives/scholarship-program/>

180 Medical: Open to students with Spina Bifida, neurogenic bladder, spinal cord injury, and/or transverse myelitis. Available to two-year, four-year, or graduate school program full time in the fall are eligible to apply.

<http://www.180medical.com/scholarships>



SBANENY Walk-N-Roll For Spina Bifida 2014

DATE: Saturday, May 17th
PLACE: Central Park, Schenectady, NY
TIME: Morning –
details to be announced soon

It's time to gather your family, friends, neighbors, and co-workers. Who will be on your team this year?



Aly McDonald has been busy for the past many months raising awareness in her hometown and money for her Walk-N-Roll team. Visit her website

<http://alysaim.weebly.com/>.

You are bound to be inspired by all of her energy and enthusiasm!

Join the Walk-N-Roll Planning Committee!

WHEN: Wednesday, January 22nd at 6:30 PM
WHERE: SBANENY office, 123 Saratoga Road, Scotia

Can't be here in person? Call in by conference call, or talk to Heather and find out what you can do to help.

SBANENY: HOW WOULD YOU LIKE TO GET INVOLVED?

- ✓ Skills in **Graphic Design**
- ✓ Expertise with **databases &/or Microsoft Access**
- ✓ **Picnic coordinator** for May 17th
- ✓ **Clerical tasks**
- ✓ **Party planning** – Join the committee for the annual fundraiser or the picnic.
- ✓ **Worker bees!** No coordination required!

If your answer is yes to any of the above, or you have ideas of how you might be able to help, **please contact our office today.**



Your time and talents can make a difference today!

DARE TO DREAM WITH SBANENY 20 YEARS...

LOOK HOW FAR WE HAVE COME!

Our annual fundraiser took place on December 7th at the Silver Hills Restaurant and Banquet House. Attendees enjoyed holiday music from The Singing Anchors and participated in a large silent auction created through hundreds of generous donations.



In celebration of the 20th anniversary of the founding of Spina Bifida Association of Northeastern NY (SBANENY), the Board of Directors recognized those who worked in the early days and without whom SBANENY would not exist. Each year SBANENY provides services and support to people living with Spina Bifida and their families, thanks in part to their vision and commitment to our community in the early days. Their work continues on.



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RETURN SERVICE REQUESTED

SBANENY CALENDAR OF EVENTS

- JANUARY 18** Building Healthy Relationships
- FEBRUARY 22** Middle Adults Luncheon
- MARCH 1** Frank Bucino Memorial Scholarship
(Anticipated application deadline)
- EARLY SPRING** Greater NYC metro area program TBA
- MAY 1** Helen Mertens Scholarship Application Deadline
- MAY 17** SBANENY Walk-N-Roll for Spina Bifida 2014
- MAY 17** SBANENY Family & Friends Picnic
Programs for Families with Children
- SEPTEMBER 6** SBANENY sponsored regional conference
- OCTOBER 24 – 26** Fall Family Weekend, Double H Ranch
- LATE FALL** SBANENY Annual Fundraiser TBA soon!

WATCH FOR FLYERS,
FACEBOOK UPDATES,
EMAILS, AND OUR
WEBSITE FOR
INFORMATION ABOUT
ADDITIONAL EVENTS
AS PLANS ARE
ANNOUNCED.

SBANENY BOARD MEETINGS March 8, May 10, 2014

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.