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MESSAGE FROM THE CHAPTER CHAIR

Dear SBANENY Friends,

It looks like spring is finally here at least for now. I'm sure you will all agree it's been a long winter. It's good to be able to go outside and not run into mountains of snow!

SBANENY is a very busy place. Our committees are working hard to put together some great programs and activities. On May 17th we will have our 4th annual Walk and Roll in Schenectady's Central Park. The Walk will be followed by a picnic. The committee has added many fun contests to this year's event. Have you registered yet? Check our website for more information.

This summer, the Adult Group will be hosting a "Ways to Advocate" ice cream social. The Families with Children committee is planning a June outing. Look for more information on both of these events coming soon.

On September 6th, SBANENY will be hosting a regional Spina Bifida conference. Have you saved the date on your calendar? Read the article enclosed for more information about the conference

Finally, on November 15th we will be celebrating with our annual fundraiser, Dare to Dream with SBANENY – Celebrating Our Successes! The evening will include a live and silent auction fundraiser. Everyone can help by asking family and friends to "Save the Date". It's not too early to do that! See inside for details.

SBANENY is always trying to come up with different ways to connect with individuals and families and to help you connect with each other. If you have any ideas you would like to share with us, please contact our office or visit us online via our website or Facebook.

I hope to see you and your family at one of our events and activities soon.

**Shameka Andrews
Chapter Chair**

SBANENY

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James Dunham, Vice Chair

Stephanie Mumford, Treasurer

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Kevin Chamberlain, Past Chair

Amy Clinton

Raymond Langelier

Lyndsi Holmes

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SBANENY NEWS

MIDDLE ADULTS LUNCHEON

As part of our regularly scheduled get togethers, adults met at the office in Scotia over lunch to discuss ideas about future programming. The group stressed that the focus needs to continue to be sharing information about what has worked in our lives that will lead us all to greater health and satisfaction.



In keeping with that theme, **on May 10th the group will meet to talk about exercise.**

Participants are asked to bring information (books, pamphlets, DVDs), that demonstrate activities that people with Spina Bifida may find helpful in keeping fit. Look for additional information about the May 10th event on our website, Facebook, emails, or a flyer. All adults are welcome.

GAME NIGHT

On April 11 of group of eight adults gathered in Albany for games, munchies and conversation. Despite some rain, everyone had a good time. We broke up into groups and played Scrabble, Uno and Monopoly. After, the group came back together and discussed future programs and activities. We are currently planning programs for the summer and winter. More information will be coming soon!



ADULT WORKSHOP ON BUILDING HEALTHY RELATIONSHIPS

On January 18th, twelve adults with Spina Bifida gathered at the Colonie Town Library to discuss the ups and downs of building healthy relationships. We discussed personal assistance and benefits. Online dating was a very popular topic that resulted in lots of discussion. Future workshops covering similar topics were of interest to the group.

ADULT PROGRAM PLANNING COMMITTEE

Are you curious how all of these events are getting planned? Would you like to help? Contact Shameka Andrews, Barbara Devore, or our office for information.

NEW YORK CITY AREA PROGRAMS KICKOFF EVENT

Are you or your child living with Spina Bifida? Do you live in New York City or the surrounding area? We are facilitating a meeting of people in your area.

Who: Children and adults with Spina Bifida and their families

What: Kickoff event for our NYC Area group

- **Presentation:** *"Accessibility and Recreation in the City"*
- Meet other individuals with Spina Bifida in the greater New York City metropolitan area

When: May 10, 2014 from Noon to 2 PM

Where: Manhattan Borough President's Office, One Centre Street, 19th Floor South, NY, NY

Questions? Reach us through Facebook, rachael.strohl@sbaneny.org, or 518-399-9151.

Please **RSVP by May 1st** to Rachael at rachael.strohl@sbaneny.org.

SBANENY NEWS

LET'S GO BOWLING!

A group of our families with children met on March 29th for an afternoon of bowling and pizza. As with any of these events, this was a wonderful opportunity for parents to connect with each other and the children to develop and strengthen friendships. So while the activity was bowling, the bonus was networking and support.

The next event for families with children with Spina Bifida is being planned for June. Details will be announced soon so watch for it through emails, flyers, our website, and our Facebook page!



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

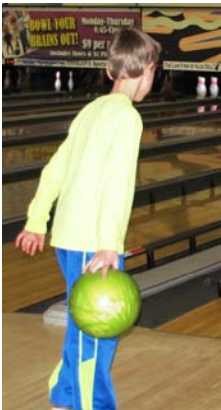
FEE: There is no charge to participate.

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 and let her know what you can do to help out with this.

Want to learn more about upcoming SBANENY programs and services?

- Follow us on Facebook
- Visit our Website at www.sbaneny.org
- Watch for emails & flyers
- Check your phone messages
- Contact our office anytime with questions!



We didn't count how many strikes we got, but families had a great time!



SBANENY NEWS

EMPOWERMENT THROUGH ADVOCACY:

LIVING WITH SPINA BIFIDA SBANENY TO HOST 3RD REGIONAL CONFERENCE

DATE: Saturday, September 6, 2014

TIME: 9 AM to 4:30 PM

PLACE: Bryant & Stratton College, Albany

SESSION TOPICS will include advocacy as it relates to insurance, healthcare, benefits, employment, & education.

SCHOLARSHIPS: We anticipate that assistance will be available to help defray costs for attending the conference including registration, travel, and lodging expenses.

Watch for more information soon. *In the meantime, be sure to mark the date on your calendars!*

SCHOLARSHIP OPPORTUNITIES

FRANK BUCINO JR.

MEMORIAL SCHOLARSHIP

&

HELEN R. MERTENS

EDUCATIONAL SCHOLARSHIP



These two scholarships, managed by SBANENY, offer up to \$1,000 each in financial assistance for educational purposes, including attendance at the national Spina Bifida Association. Are you in school and paying for tuition or related educational fees? Would you like to participate in the national conference? Visit our website at www.sbaneny.org or contact our office for more information and application forms. (admin@sbaneny.org, 518-399-9151.)

*Sponsored by Spina Bifida Association of
Northeastern New York*

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.

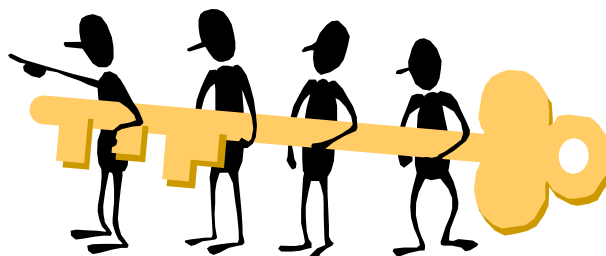
The following items are available, for anyone who might be in short supply on a temporary basis.

- ✓ Medium size Depends
- ✓ One size fits all belted continence shields

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

Do you have equipment or supplies that you are no longer using and would like to pass on to someone else who could use it? Let us know and we will see if we can find a home for it!

MANY HANDS THE KEY TO MAKING LIGHT WORK!



How would you like to be involved?

- ✓ **Publicity** Coordinator, Annual Fundraiser
- ✓ 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!

SBANENY NEWS



SBANENY Walk-N-Roll For Spina Bifida 2014

DATE: Saturday, May 17th

PLACE: Central Park, Schenectady, NY

TIME: 8:30 AM Check-in begins (bagels & beverages included!)

9:30 AM Opening Ceremonies

10 AM Walk begins

11:30 to 1 SBANENY Family & Friends Picnic

REGISTRATION: Register online before the event and save yourself waiting in line on May 17th! [Register Here!](#)

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

SBANENY Walk-N-Roll Contests!

- ✓ Individual raising the most money
- ✓ Team raising the most money – How are you doing on building your team?
- ✓ Team Name
- ✓ Team Spirit – Has your team started your t-shirt or other apparel? How about your team banner?

Earn prizes and tickets toward raffles. SBANENY Walk-N-Roll for Spina Bifida 2014 presented by The Daily Gazette followed by our Family & Friends Picnic promises to be a great day!

USED EQUIPMENT TO SELL OR BUY?

Looking to buy or sell any used equipment? Sportsabilities website has a "classified" section right on their website! Items range from bicycles and wheelchairs to skis and vehicles! Check it out at www.sportsabilities.com.

ALY'S AIM FOR AWARENESS

Aly McDonald got an early start with her Walk-N-Roll Team, walking to raise awareness about Spina Bifida in her hometown of Malone. She and her family hosted a pre-Walk-N-Roll walk on April 5th. Aly plans to be at our Walk-N-Roll on May 17th. Be sure to say hello and thank you to her!

For more information about Aly's projects, visit her website [Ay's Aim for Awareness](#). Aly, thank you for your energy and enthusiasm!



SBANENY board member Michelle Miller presents Aly with a Certificate of Appreciation for all of her efforts.

DARE TO DREAM WITH SBANENY: CELEBRATING OUR SUCCESSES!

DATE: November 15, 2014

TIME: 6 to 9 PM

PLACE: Pinehaven Country Club, Guilderland

ENTERTAINMENT: Music by Shadowland

Live & Silent Auction!

SAVE THE DATE!

**ASK FRIENDS & FAMILY
TO SAVE THE DATE TOO!**

**Join the Dare to Dream with SBANENY
Annual Fundraiser Planning Committee!**

NEXT MEETING: Tuesday, May 13th

WHERE: SBANENY office, 123 Saratoga Road, Scotia or call in by conference call.

Questions? Why do we need you? Talk to Karen or Bobbie to find out about how what your part in this important event can be!

SBANENY NEWS

SEEING THROUGH THEIR EYES, HEARING THEIR HEARTS

The Independent Living Center of the Hudson Valley (ILCHV), located in Troy, is seeking applications for its new 6 week photojournalism class. "Seeing Through Their Eyes, Hearing Their Hearts" will give participants (ages 18 and above) a chance to work with an artist to write about their own disability experience and pair it with photographs taken by the participants that speak to their experiences in pictures. The class begins Tuesday June 3rd from 5 to 6:30 and runs weekly through July 15th (no class on July 1st). The class will culminate in an exhibition in the late Fall, hosted by ILCHV and the participants. The class is free and no prior experience writing or taking pictures is required. Interested? Please call Barbara Devore at 274-0701 or e-mail her at bdevore@ilchv.org for an application and more information.

ACCESS TO HOME PROGRAM

Albany Community Action Partnership (ACAP) Access to Home services are available to both renters and homeowners who have permanent physical disabilities or experience difficulties with daily activities. This program is designed to assist people of all ages, including elderly who are no longer able to easily move in their own homes. Total household income cannot be greater than 80% of the local area median income [120% of area median income for disabled veterans]. In Albany County this typically requires household income to be less than \$45,000/year. For more information, visit the website at www.albanycap.org.

Like [SBANENY](#) on Facebook!

NATIONAL SPINA BIFIDA ASSOCIATION NATIONAL CONFERENCE

When: June 29 – July 2, 2014

Where: Disneyland – Anaheim, California

Information and online registration is available on [Spina Bifida Association's conference website](#).

PLEASE NOTE: Both the Bucino and the Mertens scholarships sponsored by SBANENY can be used toward expenses related to attending the national conference. Information is available at these links: [Frank Bucino Jr. Memorial Scholarship](#) and [Helen Mertens Educational Scholarship](#).

CHANGES TO NYS SUPPLEMENT PROGRAM

The New York State Supplement Program (SSP) provides state-funded financial assistance to people who are aged, blind or disabled. SSP is part of the monthly benefit paid to most Supplemental Security Income (SSI) recipients. Until October 1, 2014, New York State residents who receive SSI/SSP benefits will receive one payment from the Social Security Administration (SSA) that combines the federal SSI benefit and the New York State SSP benefit. Starting October 1, 2014, New York SSI/SSP recipients will get the federal SSI benefit and the state SSP benefit separately. The SSP Bureau in the Center for Employment and Economic Supports within the NYS Office of Temporary and Disability Assistance (OTDA) will operate the program.

- The only change that SSI/SSP recipients will experience is the receipt of two monthly payments rather than one.
- SSP recipients will receive their SSP benefits in the same manner that they receive their SSI benefit. Direct deposits, including deposits into Direct Express accounts, will go into the same account and payments will be issued on or before the first of each month.

A Local Commissioners' Memorandum which describes the SSP takeover process, including those changes that will impact SSDs, will be issued during late summer 2014.

SBANENY NEWS

UNITED HEALTHCARE CHILDREN'S FOUNDATION (UHCCF) GRANTS

UHCCF grants provide financial help/assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan. The Foundation aims to fill the gap between what medical services/items a child needs and what their commercial health benefit plan will pay for. Grant applicants must be 16 years or younger and have a commercial insurance plan.

For more information or to apply, visit the foundation at www.uhccf.org.

NEW WEBSITE GEARED AT NY VOTERS WITH DISABILITIES

The Center for Disability Rights (CDR) is excited to announce the launch of the website for the New York Disability Vote Network (NYDVN), accessed at www.nydvn.org. The ultimate goal of the 2-year project is to build, solidify, and unify a disability voting bloc in the state of New York. A database of voters with disabilities will be the first of its kind in New York State, and will serve as a vehicle for promoting a disability-friendly nonpartisan agenda. The NYDVN project is a unique collaborative effort to provide a political voice to an often overlooked population. Current areas of focus include health care, housing, transportation, and employment.

The NYDVN project is made possible with a grant from Adult Career and Continuing Education Services – Vocational Rehabilitation (ACCES-VR). Voting age individuals with disabilities and other interested parties are encouraged to join the network by filling out an online form that can be found on the website. Volunteers are also welcome. For more information, please contact Jessica Thurber, Voter Rights Coordinator at CDR. Website: www.nydvn.org / www.cdrnys.org

CONTACT:

Jessica Thurber, Voter Rights Coordinator,
Center for Disability Rights
Contact: 443-529-0703, jthurber@cdrnys.org

SUMMER PLANS – CIRCLE OF CHAMPS

Circle of Champs is a program dedicated to improving the quality of life for children who've been touched by a life-threatening illness. Free of charge, kids are welcome to join a week of fun with the YMCA Adventure Camp in Guilderland and a week of summer fun at the Bethlehem YMCA. For more information, contact Jenna Jura at 518.456.3634 x 1120.

GIRLS WITH DISABILITIES ARE AMERICAN GIRLS TOO

*From Sportsabilities

Melissa, a bright and adorable 10-year-old is petitioning the American Girl brand to name a doll with a disability as its 2015 "Girl of the Year" because "disabled girls are American girls too," she says. Melissa has Charcot-Marie-Tooth disease, which damages the peripheral nerves, causing muscle weakness and decreased muscle size, according to the Mayo Clinic. She uses a wheelchair.

Melissa's petition says: "For once, I don't want to be invisible or a side character that the main American Girl has to help: I want other girls to know what it's like to be me, through a disabled American Girl's story. Girls (who have disabilities) might be different from normal kids on the outside.... However, we are the same as other girls on the inside, with the same thoughts and feelings. American Girls are supposed to represent all the girls that make up American history, past and present...."

Melissa launched a petition on Change.org titled "American Girl: Release an American Girl with a disability." You can find the petition on Change.org and sign to help make her dream come true!



SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK

NONPROFIT ORG
US POSTAGE
PAID
Burnt Hills, NY
PERMIT NO. 6

123 Saratoga Road
Scotia, NY 12302

RETURN SERVICE REQUESTED

SBANENY CALENDAR OF EVENTS

- MAY 1** Frank Bucino Memorial Scholarship
Helen Mertens Educational Scholarship
- MAY 10** Adults – Sharing Activities for Keeping Fit
Greater NYC metro area program
- MAY 17** SBANENY Walk-N-Roll for Spina Bifida 2014
SBANENY Family & Friends Picnic
- JUNE TBA** Program for Families with Children
- SEPTEMBER 6** SBANENY sponsored regional conference
- OCTOBER 24 – 26** Fall Family Weekend, Double H Ranch
- NOVEMBER 15** SBANENY Gala: Dare to Dream with SBANENY – Celebrating Our Successes

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

SBANENY BOARD MEETINGS May 3, July 12, September 13, and November 8

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.