



SBANENY News to Use

CHAIR LETTER

Happy Summer!

It is with the spirit of making connections that our executive director Karen and I headed to Minneapolis, Minnesota for the 41st National Spina Bifida Association Conference. Every other year people from across the country whose lives are touched by Spina Bifida come together to attend conference sessions from some of the nation's leading doctors, researchers and other professionals in their respected fields. Personally, I had not attended national conference since I was a young child, so the opportunity to increase my network of adults with Spina Bifida was very appealing.

This year national conference was attended by over 700 people. If you came to our chapter conference this year, you know how powerful it is to be with new and old friends and their families from across the state. National conference is like that but on a bigger scale. I had the privilege of meeting other people with Spina Bifida from all over the country, people who understand what it means to live with Spina Bifida and who I could relate to on an incredible level. I also met families with young children who have Spina Bifida. For them, I think it was powerful to see the range of possibilities that lay ahead for their children.

While the conference was a wonderful opportunity to meet new people, there were also presenters on a variety of topics, ranging from urology and neurology, to health and fitness, to advocating for yourself and reaching your full potential. National conference brings together some of the nation's top experts and gives participants the opportunity to ask questions to increase their quality of life. At SBANENY, we frequently talk about resources throughout the state and how much it varies from city to city. On a national scale that variety is even more obvious. Whether you have some information and resources on a certain topic or none at all, it is interesting to hear what other professionals have to say and to compare with what you know.

While, through the power of social media, I can stay in contact with people I met at national conference, the face to face connection is invaluable. I hope to be able to attend the 42nd National Spina Bifida Association Conference in 2018. If you are interested in attending the conference as well, we encourage you to keep a look out for information on-line. Then as we get closer there is information on our website (www.sbaneny.org) about scholarships that are available to help cover some of the costs of the conference. As always you can reach out to the office for more information.

Stay cool this summer and we hope to see you at our fall events that you can read about in this newsletter!

Lyndsi Holmes-Wickert, Board Chair

ISSUE #68
JULY 2016

SBANENY Walk-N-Roll

Dare to Dream

Upcoming Events

Equipment Exchange

Getting Involved

SBANENY Updates

National SBA Conference

Staying Informed

Calendar of Events

SBANENY BOARD

Chair: Lyndsi Holmes-Wickert

Vice Chair: Michelle Miller

Past Chair: James Dunham

Treasurer: Heather Green

Secretary: Margaret Smith

Directors:

James Alescio

Peggy Felt

Annmarie Fennicks

Margaret Huff

Executive Director

Karen Wentworth

Mark your calendar!

Upcoming SBANENY events



Dare to Dream with SBANENY

Live & Silent Auction

Appetizers, Dessert & Entertainment

November 19, 2016

6:00 to 10:00 PM

Wolferts Roost Country Club, Albany, NY

Honoring Max Yurenda, Double H Ranch

Honorary Chairs Richard & Theresa Sleasman, CBRE-Albany

There are many ways to Dare to Dream with SBANENY!

- ♦ Become a sponsor
- ♦ Join the honorary committee
- ♦ Place an ad in the event program
- ♦ Donate an item for the silent auction
- ♦ Plan to attend Dare to Dream with SBANENY on November 19th

For more information,
please visit our website or contact our office.

Y-Knot Accessible Sailing

YMCA Camp Chingachgook

Keep an eye out for more information as we continue to organize this program as one of our summer events. If you are interested, let us know ahead of time!

Tel: 518-399-9151

Email: casemanager@sbaneny.org



FALL FAMILY RETREAT

At the Double H Ranch

97 Hidden Valley Rd.
Lake Luzerne, NY 12846

Friday, October 21 - Sunday, October 23

Keep an eye out for registration forms becoming available at the end of this summer!



Equipment Exchange

As part of the July 2016 Newsletter, SBANENY is making an effort to help **connect individuals and families in need of equipment or supplies with those who are looking to donate**. In addition, we connect people who have equipment they no longer need with organizations who accept donations, facilitate equipment exchanges, and provide equipment at a lower cost.

***PLEASE NOTE: SBANENY is not accepting donations of equipment or supplies to our office** due to a lack of storage space. Our goal is to facilitate the connection for exchanges to occur directly between the person donating and the person in need. In addition, we cannot guarantee the quality of equipment being donated or the circumstances in which the exchange will occur. We hope this addition to the newsletter will help us better serve our consumers! *

If you are interested in one of the items listed that is available for donation, or have an item you are willing to donate that is listed on the need/wanted list, **please contact the office so we can help get you connected!** Telephone: 518-399-9151 Email: casemanager@sbaneny.org

Individuals/ Families looking to **donate**:

- Child's wheelchair (5-6 years old)
- Child's walker (5-6 years old)
- (2) Adult walker
- Adult crutches
- Catheters
- Power chair (pictured on the right)



Individuals/ Families looking to **receive**:

- Kid's hand-cycle
- Adult hand-cycle
- Young adult outdoors motorized scooter

Agencies and organizations to consider:

- **Jezreel:** Accepting personal care items, medical equipment and supplies (<http://www.jezreelinternational.org>)
- **Joni and friends: Wheels for the worlds.** Accepts donated wheelchairs (<http://www.joniandfriends.org/wheels-for-the-world/>)
- **Lending Closet at Suffolk Independent Living Organization:** Houses over 300 pieces of donated equipment available for lending until the item can be obtained independently (<https://www.siloinc.org/services/traid.php>)
- **Southern Adirondack Independent Living Center Medical Equipment Access Assistance:** Provides loans of assistive technology and medical equipment (<http://sailhelps.org/services/equipment/>)
- Contact your local Independent Living Center whether you are looking to donate or receive equipment!

Looking to get involved in something new? Consider these options!

ATTEND A COMMUNITY EVENT

FRANK BUCINO JR. MEMORIAL

SCHOLARSHIP FUNDRAISER

The Frank Bucino Jr. Scholarship is a SBANENY scholarship awarding financial assistance to individuals with Spina Bifida to support education or conference attendance. **The Bucino family is hosting a fundraiser to raise funds available for this scholarship. Consider attending the event or sharing the provided information** to help us continue supporting individuals as they pursue education or attending a conference.

Where:

Grange Hall
158 County Road 32A
Norwich, NY 13815

When:

Wednesday September 7, 2016
from 11 am-6 pm

Food will be provided by Doug's Fish Fry Mobile Truck. A percentage of net sales to the funds being donated.

- If you want to call in orders on the day of the event you can do so from 11-4 at 607-423-5996.
- Weather permitting, the event will take place outside
- Inside seating available.



Creators of Beauty: Hand Painted Quilt Squares.

The Independent Living Center of the Hudson Valley (ILCHV) and Jeannie Thomma are presenting a **FREE** workshop to create a community quilt.

Participate in a three week class to learn to felt wool by hand. You will create two felt panels and sew them on to canvas squares. One of your squares will be sewn into the community quilt for display at the ILCHV and the other will be yours to take home!

When: August 2, 9, & 16 from 5:30-7:30 with refreshments available from 5-5:30.

Where: Independent Living Center of the Hudson Valley: 15-17 3rd St., Troy, NY 12180

- No formal experience required and all materials will be provided
- You must RSVP to participate. Contact Barbara Devore at 518-274-0701 or bdevore@ilchv.org no later than July 27, 2016 to ask questions and participate in this opportunity!

PARTICIPATE IN A SPORTS PROGRAM

Helen Hayes Adapted Sports & Recreation

Kayaking, Waterskiing, Glider Plane Outing, Archery & Airsoft Target Shooting options are still available this summer!

Visit the website and check out the calendar of events: <http://helenhayeshospital.org/calendar/>

JOIN A SBANENY COMMITTEE

- Conference/ Education Day
 - Walk-N-Roll
 - Dare to Dream
 - Young Families
 - NYC Planning
 - Adult Group

If you are interested in learning more about our programs and committees, contact us at the office!

518-399-9151 / casemanager@sbaneny.org

Spina Bifida Association National Conference

Beyond All Limits

National SBA Conference

Submitted by Karen Wentworth, Executive Director

The Conference

For four days at the end of June, over 750 people traveled from around the country to Minneapolis, Minnesota for the national Spina Bifida Association biennial conference. Those attending included adults of all ages with Spina Bifida, parents of children with Spina Bifida, and children with Spina Bifida and their siblings. Also in attendance were leaders of affiliated chapters of SBA and health care providers who serve people with Spina Bifida. I was privileged to attend the conference with the SBANENY Board Chair, Lyndsi Holmes-Wickert.

My Experience

This was the fifth such conference that I have attended as a representative of SBANENY. I find the experience of great value to my work for this organization and the individuals and families that we serve. As with our local conference, I not only learn from the presenters, but from the other people attending the conference on a variety of related topics: bowel and bladder management; hydrocephalus and shunts — care and management; non-verbal learning issues; aging and Spina Bifida; orthopedic needs and challenges to name a few. In addition to sessions with professional presenters, there are a variety of sessions that are peer led presentations and discussions which provide opportunities for people to learn from each other. Imagine having over sixteen topics to choose from in any given day!

Vendors

In between sessions, there is always a meal to share or a vendor to visit. Of note this year were the variety vendors whose businesses are geared to greater accessibility to home, community, and the world. Among the vendors present, there were wheelchair vendors, their products ranging from a scooter for under age 3, to a FreeWheel attachment that turns a standard chair into a 3-wheel all-terrain chair, to the Action Trackchair, also designed for all-terrain. Two travel agent companies were available that offer services to travelers with disabilities to assist with planning travel that will meet particular special needs.

Did you know? SBANENY has scholarship money available that is intended to be used to help cover expenses for someone with Spina Bifida to attend a Spina Bifida conference. This could be a national conference such as Beyond Limits. The next national conference is expected to be in June 2018. **Are you interested in attending but would like to better understand what it might be like? Please contact Lyndsi or me through our offices.** We would be happy to speak with you about it.

What's new with Spina Bifida? Here is a small selection of the information that I picked up at the conference.

- ◇ According to information shared during the opening plenary session, **1,500 babies are born with Spina Bifida in the United States annually.** Worldwide, 300,000 babies are born with a neural tube defect with the highest rates in Southeast Asia and Africa.
- ◇ In the United States, through the Center for Disease Control, there are continued efforts to improve health for those living with Spina Bifida and address gaps and inconsistencies in health care. **The National Spina Bifida Patient Registry (NSBPR) collects data needed to evaluate medical services for patients with Spina Bifida.** Started in 2008, this will provide the information for developing best practices and protocols for health care with the goal to improve quality of care received in Spina Bifida clinics nationwide. The registry continues to grow, now with 7,000 participants ages birth to 83 years old.
- ◇ Among the findings is that **19% (1 in 5) people joining the registry report that they have pressure ulcers. Skin care wounds are the 2nd most frequent cause of hospitalization for a person with Spina Bifida.** To address this, educational materials are being developed and made available through the CDC, "Healthy Skin – Did You Look?" This will be available soon and is one example of the targeted educational information that can be developed as a result of the Spina Bifida registry data. (The most common cause of hospitalizations is urological problems.)
- ◇ Research on quality of life suggests that **people with disabilities have a higher quality of life than people without disabilities think a person with a disability will have.**

SBANENY Updates!

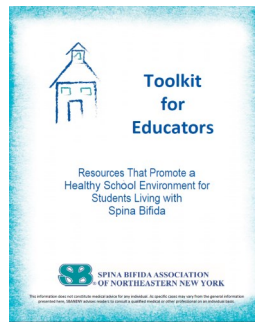
Journey Along the Erie Canal

Joined by one of our volunteers and interns this year, SBANENY attended the Journey Along the Erie Canal Reception at Price Chopper Headquarters. If you attended the 2016 Education Day, you may remember John Robinson discussing this event during his keynote speech. In alignment with the theme of our Conference, we were glad to have the opportunity to make connections while showing our support for John Robinson and Our Ability as they continue to do amazing work supporting individuals with disabilities and employment. **We look forward to the possibility of having a SBANENY team join the journey next year!**



Toolkit for Educators

As you may have seen in our April Newsletter, the Toolkit for Educators committee completed editing the Toolkit for Educators, and the final copy was printed. With the 2016-2017 school year coming up, we are expecting to distribute the Toolkit for Educators in mid-August.



Who can expect to receive a copy?

School personnel: School District Superintendents and Special Education Department/Chair person.

Parents: parents of children who are preschool– high school age (1-18). We are currently drafting a supplemental piece for parents to receive with their Toolkit giving a general overview of the education experience and process for a parent of a child with Spina Bifida.

In addition, we are planning to make a **digital copy available on our** website for educators and parents to visit and share.

SBANENY Internship Program

Since our previous newsletter where we introduced this program, we have been able to offer the SBANENY internship opportunity to another individual with Spina Bifida.

In May, 2016 Bryan Darby was accepted as the second intern to join the SBANENY team. Bryan was extremely helpful in the distribution of the 2016 Conference surveys and with the outreach for the Journey Along the Erie Canal.

We look forward to continuing to develop and enhance the program. Please address any inquires about this program to the SBANENY office!

Conference Surveys

SBANENY Conference Survey: As we consider the next conference and future programs, we are seeking your feedback in order to enhance the conference experience and increase the number of people attending who could take advantage of our speakers, vendors, and networking opportunities. Return your completed survey by **August 1st** in order to be included in the raffle for the **\$30 Amazon gift card**. If you **did not** receive a survey, but would like to share your suggestions/comments, please contact our office!

SBA launches their first Adult Health Care Survey: This survey for Adults with Spina Bifida being circulated by national SBA will help to gather demographics of the community. This information will be useful to identify research needs among other things. For individuals 18 years or older, visit this link to participate and contribute to a better future! https://www.research.net/r/sba_adult_survey

Staying Informed



HydroAssist is a mobile app that allows you to record and store your hydrocephalus treatment history and access it when you need it from your mobile device. For further information go to <http://www.hydroassoc.org/hydroassist-mobile-application/>



VIA TRANSPORTATION Center for Disability Services

VIA: Value, Independence, & Accessibility, is a shared transportation service for people with disabilities. Shared service means they may transport other individuals during your ride. VIA provides door to door services in fully accessible vehicles for individuals with disabilities.

NOTE:

- ⇒ **Riders MUST submit an application and be approved prior to using the VIA service** (applications and appointments made **online only**)
- ⇒ Rides by appointment only
- ⇒ Service is available Monday through Saturday, between 6 a.m. and 10 p.m.
- ⇒ **Serving counties:** Albany, Schenectady, Rensselaer, Saratoga, Columbia, Greene, Fulton, Montgomery, Washington and Warren

For more information on VIA, eligibility, and applying for services, visit the link:

- ♦ <http://www.cfdsny.org/htmlweb/VIA.html>
- or,
- ♦ contact the Center for Disability Services: **518-437-5700**.



Tips for Aging – Preparing your child for the loss of parents/guardians:

1. The time to start **preparing is now**.
2. Start with age appropriate **conversations** about the topic.
3. Teach **social skills** that will increase independence. Encourage and facilitate building **support relationships** beyond you as parent/guardian.
4. Go through the details. Especially as your child reaches middle teen to adulthood, they need to know who to talk to, **where important information is**, and who will be taking over any caregiving roles or needs. **Include them in this planning and decision making** as much as possible.
5. Remember to **talk to your adult child about what their role** will be in caring for you as you age.





**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

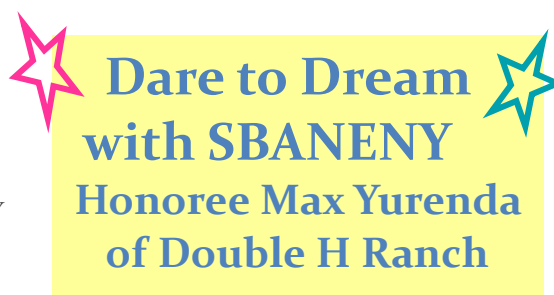
123 Saratoga Road
Scotia, NY 12302

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

RETURN SERVICE REQUESTED

***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.



**Participate through our website at
sbaneny.org.**

ABOUT SBANENY

The mission of SBANENY is to promote the prevention of Spina Bifida and enhance the lives of all affected.

SBA of NENY serves the needs of the community of northeastern New York State.

UPCOMING EVENTS

YKNOT ACCESSIBLE SAILING

August 2016, TBD

BUCINO SCHOLARSHIP EVENT

September 7, 11 AM to 6 PM

FALL FAMILY RETREAT WEEKEND

October 21–23, 2016

***DARE TO DREAM WITH SBANENY
ANNUAL FUNDRAISER***

Saturday, November 19, 2016

**FOR MORE INFORMATION
CONTACT:**

Karen Wentworth
admin@sbaneny.org
t (518)399-9151
f (518) 399-5639
sbaneny.org

***COMMITTEES TO JOIN
& Next Scheduled Meeting***

Walk-N-Roll (September TBA)
Dare to Dream (8/9, 6:30 PM)
Board of Directors (9/10, 9 AM)
SBANENY Education Day (TBD)
Toolkits for Educators
Young Families (TBD)
Adult Group (TBD)
NYC Metro Planning Group (TBD)

SBANENY Walk-N-Roll for Spina Bifida 2016

*Thank you to the
Walk-N-Roll Committee,
individuals, families,
providers, and volunteers
who made the SBANENY
Walk-N-Roll possible!*



Find more pictures on Facebook
or the SBANENY website!
www.facebook/SBANENY
www.sbaneny.org



Dare to Dream with SBANENY

Live & Silent Auction

Appetizers, Dessert & Entertainment

November 19, 2016

6:00 to 10:00 PM

Wolferts Roost Country Club, Albany, NY

Honoring Max Yurenda of Double H Ranch

Honorary Chairs Richard & Theresa Sleasman, CBRE-Albany

*To benefit the programs and services of Spina Bifida Association of Northeastern New York
On the evening of November 19th, come mingle with friends and colleagues at Wolferts Roost Country Club.
Enjoy music and dancing with the band Fresh of Albany. Heavy hors d'oeuvres, desserts, and a cash bar.
Browse our extensive silent auction. Join in the action and excitement of the live auction!*