



SBANENY News to Use

CHAIR LETTER

Hello! I hope everyone had a great summer and you are enjoying the colors of fall.

The last few months have been busy at SBANENY and we have good things still ahead for the remainder of the year. In July, a group of us got together for an afternoon of Y-Knot sailing hosted by Camp Chingachgook. It was beautiful weather and everyone had a great time. In August, SBANENY consumers enjoyed a Tri-City ValleyCats game, funded by SBANENY and a grant from WGY Christmas Wish. Save the date for our upcoming Adaptive Dance Workshop being hosted by Roll Call Wheelchair Dance and taking place on Sunday, November 19.

The Search and Transition committee has been busy looking for SBANENY's next Executive Director. By the time this newsletter is published, the job will be reposted. You will see emails and Facebook posts related to this. We appreciate your assistance to help us find strong candidates. Please share the Job Post insert with your networks.

The SBANENY board had their annual retreat on September 30th. This meeting provides an opportunity for training and in-depth discussions. This year we were fortunate to have Eileen Nash, Director of Development from Double H Ranch, present and facilitate discussions on "Creating a Fundraising Tool Box." Our board is working hard to grow SBANENY's income so that we can continue to respond to the needs of the Spina Bifida community in our state.

How can you help meet these needs? Consider the skills and talents that you can offer to SBANENY as volunteer. Participate in the "8 for 8" Campaign for Spina Bifida Awareness Month. Purchase your tickets for Dare to Dream with SBANENY. Watch for our Annual Report and Mail Campaign in early December. Finally, share information about all of these opportunities with your networks. With all of us working together, SBANENY will be available to provide quality services and support to individuals living with Spina Bifida and their families.

Thank you,
Shelley Miller, Board Chair

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ISSUE #73 OCTOBER 2017

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SBANENY BOARD

Chair: Michelle Miller
Vice Chair: Margaret Smith
Immediate Past Chair:
Lyndsi Holmes-Wickert
Treasurer: James Alescio
Secretary: Peggy Felt
Directors:
Kevin Chamberlain
James Dunham
Annmarie Fennicks
Heather Green-Kirk
Margaret Huff
Gloria Zampini

Executive Director
Karen Wentworth

SBANENY UPDATES

OUTREACH AND ACTION

Keep an eye out for surveys in the upcoming months. We are seeking feedback and input on SBANENY programming.

- ◇ Program ideas & suggestions
- ◇ Prior program feedback
- ◇ Planning committee interest

Survey respondents will be entered in a drawing to win a prize!

Thank you to the Albany Rotary Foundation for your support to make this possible!

COMMUNITY INVOLVEMENT

Thank you to our families and friends who help raise awareness and donations for SBANENY.

Grand Slam for Spina Bifida

Thank you Jeff & Kayt for choosing SBANENY as the charity receiving donations from your softball tournament this summer.



Delilah's Fundraiser

Delilah held a week long Jump-A-Thon fundraiser at her school to support SBANENY in the spring.

Viaport

In support of Spina Bifida Awareness Month, Viaport is raising donations at the aquarium by selling \$1.00 fish as seen below!



FALL FAMILY RETREAT

Double H Ranch generously offers this program at no charge to individuals ages 5-21 living with Spina Bifida, siblings, parents or guardians.

Join us for a three day weekend of FUN.

Thursday, October 26-Sunday, October 29

Ropes course, archery, swimming, pumpkin carving, adaptive yoga, fashion and more!

Applications available on the SBANENY website. Pre-registration is required.

ZIP LINE



SBANENY EDUCATION DAY

SAVE THE DATE

4-14-18



SBANENY is planning our 5th Education Day to take place on Saturday, April 14, 2018 at the SUNY School of Public Health.

This year's conference theme is...

Empowerment Through Planning for the Future

Stay tuned for a schedule, speakers, vendors and more!

MARK YOUR CALENDAR!

NYS DEPARTMENT OF HEALTH

SBANENY staff recently met with the Division of Family Health of the NYS Department of Health. We received information on programs and services that would be helpful for our families. See below for a short summary of what we learned!

Early Intervention (EI)

Public health law and regulations require that primary referral sources refer children with disabilities or at risk of having disabilities to their local EI Program.

Eligibility: Child is under three years of age and has a confirmed disability or established development delay in one+ area of development (physical, cognitive, communication, social-emotional, and/or adaptive).

EI offers therapeutic and support services to eligible infants and families. The website offers a Parent's Guide and further information for families.

https://www.health.ny.gov/community/infants_children/early_intervention/

Children with Special Health Care Needs (CSHCN) Program & Physically Handicapped Children's Program (PHCP)

CSHCN: This program provides information and referral services for children birth-21 with a serious or chronic physical, developmental, behavioral or emotional condition. Information and referral services are provided for public insurance and other government programs, community services and programs, and family organizations and support groups. For more information: https://www.health.ny.gov/community/special_needs/. This is located in 28 counties in NYS; check your county here: https://www.health.ny.gov/community/special_needs/county_programs.htm

PHCP is the financial component to CSHCN. PCHP assists families in paying medical bills. There are two components: the Diagnosis and Evaluation Program (D&E) and the Treatment Program. The D&E Program will reimburse specialty providers for the diagnosis and development of a treatment plan for eligible children. The Treatment Program will reimburse specialty providers for the ongoing health and related services for children who are medically and financially eligible in their county of residence. For more information: https://www.health.ny.gov/publications/0548/children_special_health_care_needs_including_phys_handi_children.htm

Multiple Systems Navigator (MSN)

MSN provides access to helpful health, education, human service and disability information on one user-friendly website. It is built for youth, parents, family members and caregivers that rely on supports from multiple child and family serving systems. The mapping tool helps the user to find community, disability, childhood, education, family support and peer advocacy, medical/physical and mental health programs and services.

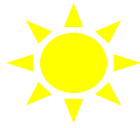
<http://www.msnavigator.org/>

Medicaid Health Homes

A Medicaid Health Home is not an actual home, but a group of health care and service providers working together to make sure you get the care and services you need to stay healthy. For children who have Medicaid, families are assigned a care manager to assist with connecting to health care providers, mental health and substance abuse providers, medications, social services or other community programs.

https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_homes/

SUMMER FUN



Y KNOT SAILING

Sunday, July 30

&

**TRI-CITY VALLEY-
CATS**

Wednesday, August 16



OCTOBER IS SPINA BIFIDA AWARENESS MONTH



\$8 FOR 8 BABIES BORN EVERY DAY

Every day in the United States, 8 babies are born with Spina Bifida or a similar birth defect. *SBANENY is asking our friends to donate \$8 to support our organization in providing support services to the individuals, families and providers in NYS.*

Donors will be entered into a raffle to win a SBANENY Dream sweater and a personal snowflake will be displayed at the office.

\$8 FOR 8 BABIES BORN WITH SPINA BIFIDA EVERYDAY IN THE UNITED STATES



#CAREABOUTSBCARE

SOCIAL MEDIA

Facebook/com/SBANENY

Submit photos to SBANENY to be featured with a Spina Bifida fact on our Facebook page

Add the #CareAboutSBCare badge to your profile photo

<http://bit.ly/sbtwibbon>

Use the hashtags #SpinaBifida & #CareAboutSBCare in your posts.

MERCHANDISE

Purchase or wear your:

I love someone with Spina Bifida Shirt (\$10)

Dream Sweater (\$20)

Cinch sacks (\$15)

Short sleeve Tees (\$15)



Dare to Dream

with SBANENY

Live & Silent Auction

Appetizers, Desserts & Live Entertainment by Fresh

Adaptive Dance Performance by Roll Call Wheelchair Dance

November 18, 2017

6:00 to 10:00 PM

Wolferts Roost Country Club, Albany, NY

Honorary Chair Jason Gough of WNYT



Thank you to our Sponsors

SOCHA PLAZA

THE DAILY GAZETTE

CBRE-ALBANY

DAVID J. KAISER BODY SHOP,
INC.

INFOED

MEDIA WELL DONE

WHITE WOLF COMPUTER

Honorary Committee

FIRST NEW YORK FEDERAL
CREDIT UNION

STICKS & STONES

RSVP TO ATTEND by contacting the office

Tickets are \$50 for guests and \$35 for consumers of SBANENY. Checks can be made payable to SBANENY

**JOIN US FOR AN ADAPTIVE DANCE WORKSHOP
HOSTED BY ROLL CALL WHEELCHAIR DANCE
THE FOLLOWING DAY**

- * **FREE**
- * Local dance studios have been invited to attend as partners
- * Sunday, November 19, 2017 from 10:30-1:30
- * Albany YMCA
- * 616 North Pearl Street Albany, NY 12204
- * Lunch provided



Please RSVP by November 1, 2017 if you would like to attend.

If you have questions about attending please contact the office!

Tel: 518-399-9151 ♦ Email: casemanager@sbaneny.org

TEN TIPS FOR LIVING LIKE A CHAMPION

1. **Get Involved** in both disability related activities (like adaptive sports or advocacy) and mainstream activities (like music, writing for your school paper, or volunteering at the local hospital). Doing something beyond school and friends lets you meet new people, discover new skills and builds self-esteem and self-confidence.

2. **Set your sights on traveling** internationally one day. Going out of the country broadens your horizons like no other experience. There are many scholarships and resources available for people with disabilities to study, work, and or volunteer abroad.

3. **Take charge of your healthcare.** Learn as much as you can about Spina Bifida and how it affects you, know your surgical and medical history (request your medical records and talk with your parents), and ask questions of your doctors.

** The “Healthguide for Adults Living with Spina Bifida” is a great resource for adults starting to manage their own healthcare. Contact SBANENY to request yours. **

4. **Be evaluated to see if driving is a possibility for you.** Being able to get around as a young adult is important to independence. If you’ve been evaluated and it’s determined by an occupational therapist that driving is unsafe for you, become the local expert on paratransit and public transportation in your area.

5. **Don’t rule out the possibility of attending a four-year university.** Dealing with learning disabilities, mobility issues and medical problems can be tough, but having a college experience will be well worth the employment opportunities it will open down the road. There are many scholarships and funding sources for students with disabilities.

6. **Be proud to have Spina Bifida.** Your disability makes you unique and contributes to many of the qualities that make you who you are. Don’t let your disability define you, but realize that you would not be yourself if you didn’t have Spina Bifida. Learn to recognize your strengths.

7. **Take risks.** No one is perfect, and you might fail or look silly as you try out new skills to be independent. Try anyway. If you never take risks you’ll never know what you are capable of doing.

8. **Develop and maintain relationships** with as many people as possible. As you begin to become independent and move away from parents, relationships with friends and mentors become more important. Create strong relationships with teachers, clergy, doctors, peers and other people that support you. The people you know are resources for you.

9. **Do physical activity every day.** Exercise is fun, it makes you feel good, it is great for your body and your emotional health. No matter what, make an effort to be active and have fun.

10. **Give back.** Volunteering, mentoring and doing community service are great ways to help others.

Author Unknown.

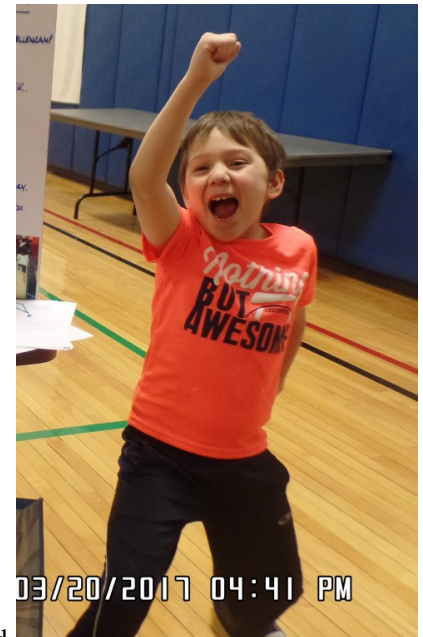
CHOOSE SBANENY FOR YOUR CHARITY OF CHOICE

Do you shop on Amazon? Did you know that by using Amazon Smile you can shop the same way but support a charitable organization?

Customers will find the same prices, selection and shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to your favorite charitable organization.

All you have to do is type smile! Simply go to smile.amazon.com and start shopping!

Please make SBANENY your charity of choice!



You shop. Amazon gives.

GETTING ACTIVE



National Center on Health, Physical Activity and Disability (NCHPAD)

Are you interested in becoming healthier? Becoming more active? Looking for new ways to exercise?

Visit the NCHPAD Website and subscribe to receive their monthly newsletter with articles on nutrition, education, research, healthcare, fitness and recreation and disabilities.

Whether it is tips for eating healthy during the holidays or adaptive strengthening exercises, you can find it here:
<https://www.nchpad.org/Articles/82/Newsletters>

JOIN A SBANENY COMMITTEE

SBANENY is always looking for volunteers to help support the programs & services through committee participation! See our committees below and contact the office for the one that you would like to join!

- ◇ Board Development
- ◇ Fundraising & Marketing
- ◇ Walk-N-Roll
- ◇ Dare to Dream with SBANENY
- ◇ Education Day
- ◇ Adult or Young Family Programming

ACCESSIBLE DESTINATIONS IN NYS

Julie's Jungle

Julie's Jungle is a playground being built for all children of all abilities. It will be the first fully accessible public playground in Dutchess County.

5 Old Lime Kiln Rd. Hopewell Junction, NY 12533.

www.juliesjungle.org

Find a list of accessible playgrounds here:

<https://www.accessibleplayground.net/>

Therapeutic Horse-riding

Pegasus Farm Chapter

Helping Hands on Horseback

310 Peach Lake Road. Brewster, NY 10509

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

Positively Playful Occupational Therapy

Hippotherapy and therapeutic riding

118 Hurst Road. Delmar, NY 12054

<http://positivelyplayfultherapy.com>

The Metropolitan Art Museum

Three NYC Locations

The Met Fifth Avenue, The Met Breuer, and The Met Cloisters.

www.metmuseum.org/

Niagara Falls

Three viewpoints, all accessible

Canadian Horseshoe Falls, American Falls, Bridal Veil Falls

Visit www.accessibleniagara.com for a full list of accessible destinations in this area!

Bronx Zoo

2300 Southern Boulevard Bronx, New York 10460

<http://bronxzoo.com/visitor-info/accessibility>

For a list accessible NYC destinations:

<https://www.nycgo.com/plan-your-trip/basic-information/accessibility?accessibilityTypes=wheelchair-accessible>

NEWS TO USE

NY ABLE

What is NY ABLE?

These are accounts for New York residents with disabilities to save for qualified disability expenses without the risk of losing certain valuable benefits they already count on like SSI or Medicaid.

Administered by: The Office of the New York State Comptroller

For more information on benefits, eligibility, using NY ABLE and more: www.mynyable.org

Questions?

Phone: 1.855.5NY.ABLE (1.855.569.2253)

Monday – Friday from 8 a.m. – 8 p.m. ET

Email: clientservices@mynyable.org

ASK A NURSE

In the beginning of September, I (Julia) shared a Bowel Management webcast through [Hollister Education](#) and families responded looking for more information on the topic. As a result, I found “Ask a Nurse” offered by the Christopher & Dana Reeve Foundation.

Nurse Linda writes about and answers Spinal Cord Injury related healthcare questions in the Ask a Nurse discussion. She is live every Wednesday from 8-9 PM ET to answer your questions. Or, you can view Nurse Linda’s archived discussions on bowel management by visiting the link below.

<http://www.spinalcordinjury-paralysis.org/forums/viewcategory/11775>

<http://www.hollister.com/en/education>

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SBA NEWS



SB-YOU

In 2018, national Spina Bifida Association is debuting their new SB-YOU webinar series where medical experts team up with adults to talk about care issues. These sessions will be FREE and archived for viewing at a later date. Keep an eye out for a schedule and registration information coming this fall.

SB STORIES

In 2018, national SBA is helping volunteers organize a Spina Bifida Stories events, bringing together storytellers and members of the Spina Bifida and disability communities to raise awareness and strengthen social networks.

SB INSIGHTS

This online magazine has stories about the Spina Bifida community moving beyond all limits! Find SBA updates and tell your own story by visiting SB Insights: www.sbinsights.org

FOLLOW MY HEALTH

Follow My Health is an online e tool that provides anywhere, anytime access to your personal health records

With Follow My Health, you can:

- Review your medical records online in a safe, secure environment
- Communicate privately with physicians via secure messaging
- View test and lab results, read medical notes from your doctor
- Update your health information (allergies, medications, conditions, etc.)
- Request prescription refills
- Schedule or change appointments
- Fill out and submit forms prior to appointments
- View and pay bills

For more information: <http://support.followmyhealth.com/>



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

123 Saratoga Road
Scotia, NY 12302

RETURN SERVICE REQUESTED

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***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.

Memorial forms are available. Please contact our office.



**Become a sponsor, plan to attend,
or donate at sbaneny.org.**

ABOUT SBANENY

Our purpose is

*Support
Health & Wellness
Awareness
Respect & Dignity
Empowerment*

UPCOMING EVENTS

FALL FAMILY RETREAT

October 26—October 29, 2017
Double H Ranch

***DARE TO DREAM WITH
SBANENY***

Saturday, November 18, 2017
Wolferts Roost Country Club
Adaptive Dance Performance

ADAPTIVE DANCE WORKSHOP

Sunday, November 19, 2017
Albany YMCA
616 North Pearl Street Albany, NY

COMMITTEE MEETINGS

Board Development— 10/16/17
Fundraising & Marketing— TBD
Education Day 2018 —10/18/17
**Dare to Dream with SBANENY—
11/14/17**
Board of Directors—11/11/17
Walk-N-Roll— January 2018

FOR MORE INFO:

Email: admin@sbaneny.org

t (518)399-9151

f (518) 399-5639

Call us toll free: 855-722-6369

COMMITTEES TO JOIN

Walk-N-Roll
Dare to Dream with SBANENY
SBANENY Education Day
Young Families
Adult Group
NYC Metro Planning Group
Fundraising & Marketing

**VISIT OUR WEBSITE —
FIND US ON FACEBOOK!**

Website: sbaneny.org
facebook.com/sbaneny

