



SBANENY News to Use

CHAIR LETTER

Happy Spring! I hope everyone had a great winter and is now ready for some warmer weather.

What better way to spend a beautiful spring day than at the 9th Annual SBANENY Walk-N-Roll for Spina Bifida? Presented by The Daily Gazette, we are grateful to these partners for all that they do to help raise awareness of Spina Bifida and this great event on May 18th. For the second year in a row, a morning 5k will take place from 8:00am-9:00am at Central Park before we kick off our Walk-N-Roll and friends and family picnic. Are you registered? Do you have a team together? Do you want to know how to get involved? Register to attend the 5k, Walk-N-Roll and friends and family picnic or both! If you don't find answers to your questions inside this newsletter, please let us know. It's sure to be a lot of fun so come out to join us!

Inside you will also read about the ways that staff, volunteers and consumers from around the state are working to raise awareness. Participants on the advocacy committee and SBANENY spent many hours during the months of January, February and March arranging for and visiting elected officials in Albany. These meetings involved education about Spina Bifida and the needs of people living with the condition, as well as providing information about SBANENY services and areas of growth. If you have an interest in learning self-advocacy skills and participating in legislative advocacy, consider joining the SBANENY advocacy committee! Or, read more inside about the National SBA's upcoming Teal on the Hill event May 6-8 in Washington D.C.

Read on to learn about upcoming Spring and Summer programs through for youth and adults living with Spina Bifida, SBANENY scholarship winners, and other upcoming events including a Car Show & Food Truck event, Eric Crow's Memorial Golf Tournament, and Dare to Dream with SBANENY.

I hope to see you at the Walk-N-Roll on May 18th!

Thank you.

Tracy Paige, Board Chair

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.

ISSUE #77 APRIL 2019

CAR SHOW & FOOD TRUCK EVENT

ADVOCACY UPDATES

SBANENY COMMITTEES AND
SCHOLARSHIPS

DARE TO DREAM

ERIC CROW MEMORIAL GOLF
TOURNAMENT

FUNDRAISING AND SPONSORSHIP
OPPORTUNITIES

SBANENY PROGRAMS

WALK-N-ROLL FOR SPINA BIFIDA

SBANENY BOARD

Chair: Tracy Paige

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Wickert

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Margaret Smith

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Chris Darby-King

Robert Derrick

Helen Eggenberger

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Julia Duff

CAR SHOW

&

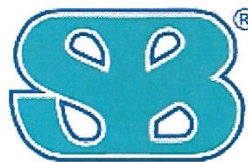
FOOD TRUCK

EVENT



**Sat., June 8, 2019
10 am to 2 pm**

to benefit



**SPINA BIFIDA
ASSOCIATION**
of Northeastern New York

at



MORRIS

FORD

872 Saratoga Rd, Ballston Lake, NY

Food Vendors Registration form:

\$50 donation to Spina Bifida of Northeastern New York

Permits: It is the vendor's responsibility to acquire all needed city and state permits of on-site activation. For more information, email Tracy Paige at tracy.paige867@gmail.com

Temporary Food Service License: Food Trucks, Vendors, and Alcohol Distributors must provide the City of Schenectady Health Department with all necessary required paperwork per Saratoga county guidelines at least 2 weeks prior to the event.

Insurance: Every participating food truck/vendor must provide a certificate of insurance that shows General liability coverage including product's coverage for limits of \$ 1,000,000 per occurrence with a \$2,000,000 aggregate. Auto liability limits of \$ 1,000,000 CSL and Workers Compensation coverage as required by the state of New York. The certificate of insurance will also name Morris Ford and Spina Bifida Association of Northeastern New York as an additional insureds.

Food Vendor Name: _____

Contact Name _____

Contact Number _____

Address _____

Check enclosed _____

Cell Number _____

Mail registration form and check to:

Spina Bifida of Northeastern New York, 123 Saratoga Road, Scotia, NY 12302

ADVOCACY UPDATE

The Spina Bifida Association of Northeastern New York participated in 20 meetings this winter with key representatives from the New York State Senate and Assembly. SBANENY staff joined by individuals living with Spina Bifida visited the Empire Plaza in downtown Albany and discussed Spina Bifida and SBANENY services. This annual project raises awareness about Spina Bifida on a statewide level, provides an opportunity to discuss the needs of the community and actions representatives can take to support those needs.

SBANENY and consumers discussed a lack of Spina Bifida specific support options for individuals and families living with Spina Bifida across New York State. Examples were shared of obstacles to receive disability related community services, insurance and benefits coverage, medical care, accessible housing and transportation, employment opportunities, and clinical care services (case management/mental health treatment). This is followed up with actions SBANENY is taking or plans to take to address those barriers. Our focus this year, was increased comprehensive case management services for all individuals and families living in New York State.

These meetings and letters shared by consumers raise critical awareness about Spina Bifida and actions that would improve the societal barriers for this community. **On Thursday, May 30, 2019, SBANENY is being introduced on the Assembly floor to acknowledge October as Spina Bifida Awareness month. An advocacy training will precede this event, and friends and family of the community are invited and encouraged to attend this introduction.**

Advocacy efforts pick back up this fall when we will be meeting with the Governor's office. The SBANENY advocacy committee will begin meeting this spring to discuss advocacy topics and strategies. As mentioned in the January edition of the newsletter, there is power in numbers. The SBANENY advocacy efforts pose an opportunity for parents, teens, and adults to develop or deepen self-advocacy skills; an opportunity to share YOUR story to affect change in society; and to learn about legislative processes. Consider joining the committee, participating in meetings, or assisting these efforts by submitting a phone call or letter to your representative. For more information on SBANENY advocacy, please contact the office.

NATIONAL SPINA BIFIDA ASSOCIATION TEAL ON THE HILL

Teal on the Hill is the Spina Bifida Association's annual advocacy day on Capitol Hill. Members of the Spina Bifida community from across the United States will create a sea of teal on Capitol Hill, advocating for issues such as continued funding for the Spina Bifida program at the Centers for Disease Control & Prevention, disability rights, and affordable and accessible health care, medical supplies, and technologies.

Check out last year's video recap: https://www.youtube.com/watch?time_continue=25&v=mnhMXXmbHdo

SBANENY will be attending the Teal on the Hill event on Capitol Hill this year.

Please keep an eye out for pictures and updates from the event on social media, in E-News, and in the July edition of the newsletter!



JOIN A SBANENY COMMITTEE TODAY!

Are you looking to give back? Meet new people? Utilize your expertise elsewhere? Consider joining one of the SBANENY committees to assist with event planning, program planning, advocacy, development and networking, and fundraising and marketing!

As an office a few staff and 100+ volunteers serving the Spina Bifida community, our volunteers are incredibly valued.

Check out some ways to get involved by reviewing the committee options below (starred committees are actively recruiting for new members this/next year):

Advocacy*
Audit, Finance & Investment
Board Development
Dare to Dream with SBANENY*

Fundraising & Marketing
Policy & Procedures
Program Planning; Young Family & Adult*
Walk-N-Roll & 5k*

Committees often meet on a monthly or bi-monthly basis; subject to change depending on the time of year.

Consider applying for a Board of Directors position!



Join a caring, compassionate and dedicated group of professionals and individuals and family members living with Spina Bifida in guiding our organization. SBANENY is actively recruiting for new members to join our Board of Directors in 2019-2020. Please be aware we are looking for specific skill sets, experience with individuals and families living with Spina Bifida, and availability when recruiting for a Board position. If you would like more information on joining the SBANENY Board of Directors for yourself or a friend, please contact the SBANENY office.

SCHOLARSHIPS AVAILABLE

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 attending an upcoming national or regional conference/educational day on Spina Bifida OR attending a school of higher education, technical training, certificate program, or driver education training.

Apply today by visiting www.sbaneny.org - Chapter Programs

HELEN R. MERTENS EDUCATIONAL SCHOLARSHIP

The Spina Bifida Association of Northeastern New York (SBANENY) has established the Helen R. Mertens Educational Scholarship Fund. The purpose of the scholarship is to award financial assistance to persons who have Spina Bifida and are pursuing higher education, technical training, or driver's education.

Congratulations to Madeline White, the 2019 recipient of the Helen Merten's Scholarship.

Madeline plans to utilize the scholarship to pursue a degree in occupational therapy. Madeline is in her second semester at SUNY Orange in the Occupational Therapy department and plans to become a Certified Occupational Therapy Assistant. Her long-term goals include becoming a licensed Occupational Therapist and eventually earn a doctorate in Occupational Therapy.

Scholarship awards remain available for 2019, applications are accepted on a rolling basis.



SBANENY PROGRAMS

Art in Mind

What: Instructed paint night for individuals living with Spina Bifida ages 7 and older

(18 years old and under must be accompanied by an adult)

Where: 123 Saratoga Road Scotia, NY 12302

When: Wednesday, June 5th, 6:30-8:30pm

Cost: Adults, \$15; Youth (18 and under), \$10.

Snacks & beverages provided.

Contact the SBANENY office for a link to the registration page!

518-399-9151 / admin@sbaneny.org



*Time to Bloom—
Painting*

Y-Knot Sailing

What: Adaptive sailing with knowledgeable skipper on a Martin 16 boat on Lake George!

Who: Adults & minors with Spina Bifida



Parents and guardians of minors are required to stay for the duration of the program. You are welcome to enjoy the day and watch from the shore!

Where: 1872 Pilot Knob Road, Kattskill Bay, NY 12844

When:

18 years old and under: Sunday, July 14th from 12:00–5:00pm

19 years old and above: Sunday, July 28th from 12:00-5:00

This program is free— lunch and refreshments are generously provided by Y-Knot Sailing.

This program is first come, first serve as there are limited sailboats. Please contact SBANENY ASAP if you would like to attend!

Tri-City Valley Cats

Join us for a baseball game!

When: Friday, August 23rd 7:00pm

Where: Joseph L. Bruno Stadium, Hudson Valley Community College, 80 Vandenburg Avenue, Troy

Who: Individuals living with Spina Bifida and immediate family members

Cost: To be determined, registration for tickets will be online



PROGRAMS IN PROGRESS/DATE TO BE DETERMINED:

- Employment Workshop
- Wellness Workshop
- Tennis Workshop
- Candle Making Event

If you have ideas for programs, connections to potential programs, interests in waiver and flyer development for programs, contact SBANENY to participate in programming for 2019-2020!

Going Green

Thank you to everyone who updated their communication preferences with us after the January newsletter. We will continue to request preferred contact methods from our families and friends in the community to do our best to communicate with people based on their preferences and help the office go green! (*See more about recycling with SBANENY on the next page.*)

If you are receiving this via USPS, our records indicate mail as your preference. If you received this via email, our records show email as your preference. **Let us know: mail, email or both!**



Dare to Dream

with SBANENY

Live & Silent Auction

Appetizers, Desserts & Live Entertainment by Fresh

November 23, 2019

6:00 to 10:00 PM

Save the date!

Join us as an attendee or consider an event sponsorship, honorary committee, or program advertisement—sponsor opportunities provided on the following page!

*You Make a Difference
Award Recipient: DJ
Lou Roberts!*



ERIC CROW
memorial golf tournament



Recycle with
SBANENY!

Clynk through Hannaford donates funds raised from bottles and cans back to SBANENY. How can you participate?

- Donate your recyclables to SBANENY and we will drop them off for you.
- Pick up a Clynk bag & tag from the SBANENY office and drop it off at your local Hannaford.

SAVE THE DATE

Eric Crow Memorial Golf Tournament

Saturday, September 28th 2019

Contact SBANENY for more information: 518-399-9151 / admin@sbaneny.org

Dare to Dream with SBANENY

Individual & Corporate Sponsorship Levels

\$5,000 Titanium Sponsor

- Acknowledgement on stage the night of the event. Opportunity to speak.
- Full-page color ad, on inside or back cover of event program and in one SBANENY newsletter
- Logo & listing, with a link to your website, on SBANENY website & 4 Facebook posts
- Acknowledgement in event press releases
- Logo placed on 10 slides during the event presentation
- Fourteen (14) tickets to the event
- Reserved table for ten guests

\$2,500 Gold Sponsor

- Acknowledgement on stage the night of the event. Opportunity to speak.
- Full-page ad in event program and in one SBANENY newsletter
- Logo and listing, with a link to your website, on SBANENY website & 2 Facebook posts
- Logo placed on 5 slides during the event presentation
- Ten (10) tickets to the event
- Reserved table for ten guests

\$1,000 Silver Sponsor

- Acknowledgement on stage the night of the event
- Half-page ad in event program & in one SBANENY newsletter
- Name listed on SBANENY website & 1 Facebook post
- Four (4) tickets to the event



\$500 Bronze Sponsor

- Acknowledgement on stage the night of the event
- Quarter-page ad in event program and name listed in one SBANENY newsletter
- Two (2) tickets to the event
-

Honorary Committee

\$275 Two Star Honorary Committee

- Two complimentary event tickets
- Listing on website and event materials

\$150 Shining Star Honorary Committee

- One complimentary event ticket
- Listing on website and event materials

Event Program Advertisements

- \$400 Full page ad
- \$250 Half page ad
- \$125 Quarter page ad
- \$ 50 Eighth page ad

For additional information contact:
Julia Duff 518-399-9151 or admin@sbaneny.org

SBANENY WALK-N-ROLL & 5K FOR SPINA BIFIDA 2019

Presented by:

THE DAILY
GAZETTE
dailygazette.com



**SIGN UP TODAY TO WALK—ROLL—RUN
OR WHEELCHAIR RACE!**

Central Park Pavilion

5K Registration: 7:30am—\$25

Walk-N-Roll Registration: 9:00am- \$5

Register, donate or sponsor
today!

www.sbaneny.org

For more
information:

admin@sbaneny.org

518-399-9151



Thank you to our 2019 Walk-N-Roll Sponsors



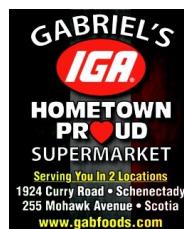
PRESENTING SPONSOR



SILVER SPONSORS



BRONZE SPONSORS





**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

123 Saratoga Road
Scotia, NY 12302

RETURN SERVICE REQUESTED

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

***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

***WALK-N-ROLL FOR SPINA BIFIDA
& 5k***

Saturday, May 18 2019
Central Park, Schenectady NY

***CAR SHOW & FOOD TRUCK
EVENT***

Saturday, June 8th
Morris Ford

***ERIC CROW MEMORIAL GOLF
TOURNAMENT***

Saturday, September 28th

DARE TO DREAM

Saturday, November 23, 2019
Wolfert's Roost Country Club

COMMITTEE MEETINGS

Walk-N-Roll— 4/30/19
Dare to Dream— May, 2019
Board of Directors— 5/4/2019

COMMITTEES TO JOIN

Advocacy
Audit, Finance and Investment
Board Development
Dare to Dream
Program Planning
Walk-N-Roll

FOR MORE INFO:

Email: admin@sbaneny.org

t (518)399-9151

f (518) 399-5639

Call us toll free: 855-722-6369

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

Website: sbaneny.org



facebook.com/sbaneny