



SBANENY News to Use

CHAIR LETTER

Happy Summer! I hope everyone is enjoying the warmer weather now that it is finally here! As the nice weather continues, SBANENY has a bunch of fun, family activities that we hope everyone will join us for. Please contact the office, look at our website (www.sbaneny.org) or read more about the activities in this newsletter if you would like to attend!

In July we are going back to Y-Knot Sailing in Lake George, NY. Y-Knot is a free, adaptive sailing program that SBANENY members have attended for the last few summers and it is always a lot of fun. SBANENY will be returning with teens and adults living with Spina Bifida on July 28th!

SBANENY is also returning to the Valley Cats! On August 23rd at 7pm we will get together to see the Capital Region's minor league baseball team. These games are always a lot of fun and a great way to catch up with old friends and make new ones. Tickets are available for \$8 per person and can be purchased on-line at our website or by calling the office. Please RSVP by August 9th.

Please save the date for our two fall fundraisers. The 2nd annual Eric Crow Memorial Golf Tournament will be September 28th, 2019 at Eagle Crest. Check out the available opportunities to participate by reading further in this newsletter! The link to register is on our website. Dare to Dream is on November 23, 2019 at Wolfert's Roost Country Club. We are excited to bring dance back to Dare to Dream this year. Roll Call Wheelchair Dance will be attending and demonstrating various styles of partner dance for standing and seated partners. We hope you join us.

As always, if there is an event you have attended in the past that you have enjoyed and/or have ideas on how to make it better, we encourage you to reach out to the office and volunteer on the planning committee. SBANENY works because of our dedicated families and volunteers who plan awesome events and we are grateful for the work everyone puts in.

Be sure to read on and check out the updates on other SBANENY fall programs, the 2020 Education Day, and medical updates for Capital District families inside this newsletter! We hope to see many of you over the next few months on the ball field, the lake, the golf course or in our office!

Sincerely,
Lyndsi Wickert
Chair, Board of Directors

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.

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SBANENY BOARD

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Margaret Smith

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Kevin Chamberlain

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Gloria Zampini

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Julia Duff

2019 Walk-N-Roll & 5K for Spina Bifida

SBANENY 5K: *Thank you to our 5K participants, Finish Right Timing, our emcee Zumba Jay, and our finish line creator Tom Ryder!*



Interested in assisting with the planning and implementation of the SBANENY 5K? Contact the office today to learn about how you can get involved!



Congratulations to our contest winners!



Team Miracle Marley, Team spirit

Kaitrin— Individual who raised the most money.

Team Kaitrin— Team who raised the most money



Thank you to the volunteer Walk-N-Roll planning committee, our day of volunteers, sponsors, vendors, and donors, the SBANENY Board of Directors, friends and families who made the 9th Annual Walk-N-Roll for Spina Bifida a success!

2019 Sponsors and Vendors

Adirondack Screen Graphics	
The Daily Gazette	Screen It, Ltd.
Hollister	DJ Lou Roberts
Mobility Works	Pepsi
Regeneron	Manhattan Bagel
CDPHP	Gabriel's Supermarket
Teal, Becker & Chiaramonte	Kaiser Auto Body, Inc.
Consumer Directed Choices	Mohawk Valley Marine
	Bard/BD



Teal on the Hill, 2019

This May, SBANENY Executive Director Julia Duff traveled to Washington, D.C. to participate in National advocacy efforts. This three day event entailed an advocacy training, updates in the needs of the Spina Bifida community, and information and research resulting from the Spina Bifida Patient Registry and Spina Bifida Collaborative Care Network. On May 8th, over 100 advocates including parents of children and adults living with Spina Bifida, youth and adults living with Spina Bifida, healthcare providers, and loved ones met with over 75 Members of Congress from 27 states to advocate for increased funding for the National Spina Bifida Program, protecting access to specialized equipment for wheelchairs, and to join the Spina Bifida caucus. See below for highlights from the 2019 Teal on the Hill!



Teal on the Hill kicked off in April with Donna Jones Testimony. Donna Jones testified in front of The House Subcommittee on Labor, Health & Human Services and Education on Tuesday, April 9, 2019. Donna is an adult from California with Spina Bifida and advocated for \$8 million in funding for the Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). The program has been funded at \$6 million, a number that has been constant for the past five years.

Watch her testimony here: <https://www.youtube.com/watch?v=dTSMhhoc7Hg&feature=youtu.be>



Funding Priorities



Fund the Spina Bifida Program at the NCBDDD at the CDC

The Issue: The only place in the federal government that is specifically studying this complex condition for children and adults is the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention through the National Spina Bifida Patient Registry and the Spina Bifida Collaborative Care Network.

THE ASK: Support an \$8 million budget for the National Spina Bifida Program at NCBDDD. The program has been level-funded at \$6 million for the past five years. With increased funding we will:

1. Fund research on sudden unexplained death among adults in the Spina Bifida (SB) community
2. Determine the number of people living with SB in the US
3. Broaden the clinic participation in the National Spina Bifida Patient Registry
4. Develop studies on social determinants of health within the Spina Bifida registry participants
5. Create a protocol for improving the health of children who have Spina Bifida with hydrocephalus
6. Research barriers to transition to adult care and analyze models for care delivery for adults with Spina Bifida

For more information on Teal on the Hill 2019, visit:

<https://www.spinabifidaassociation.org/teal-on-the-hill/>

Save the date!

Teal on the Hill 2020– April 26-28th at the same location.

Scholarships are and will be available from SBA & SBANENY!



Eric N.E. Crow Memorial Golf Tournament



The 2nd Annual Eric N.E. Crow Memorial Golf Tournament is taking place on **September 28th, 2019 at Eagle Crest in Clifton Park, New York.** This tournament is organized by Eric's mother, Helen Eggenberger-Lucas, his brother-in-law, Steven Wilday, and family. Eric passed away in 2017 after having lived an inspiring life while dealing with the difficulties of Spina Bifida. Funds raised will go to various activities and events at our Spina Bifida chapter (SBANENY), located in Glenville. SBANENY is a 501c-3 providing support services to individuals living with Spina Bifida and their families.

Eric Crow Memorial Golf Tournament Day of Events

7:00am-8:00am: Registration and Breakfast

8:00am: Golf Scramble tournament begins

Buffet Lunch: At the end of the round

Throughout the day there will be putting contests, prizes, raffles, and t-shirts available for purchase!

We cordially invite you to be a part of this event by becoming a sponsor, making a monetary or gift basket donation, participating in the golf tournament, or joining us for lunch. Please see the opportunities and commitment forms below. **Donations and registrations are due by September 1st, 2019.**

Sponsorship & Donation Opportunities:

Hole Sponsorship (\$100) includes tee sign on display at the tee box for everyone golfing to see

Table Sponsorship (\$50) includes table sign on display to be seen during the lunch buffet

Hole & Table Sponsorship (\$125) includes a tee sign and a table sign

Prize Donation: Prizes will be given away at the end of the round for the Par 3 and Putting contest. Prizes will also be raffled off at the end of the round.

Foursome Registration & Lunch for non-players

\$100 per player to participate in the golf tournament

Give-aways available for participants

\$25 for buffet lunch for non-players

Sponsor and Donor Commitment form:



Donor/Company Name: _____

Contact Name: _____

Street Address: _____

Phone: _____ **Email Address:** _____

Sponsorship Type:

_____ Hole Sponsorship (\$100)

_____ Table Sponsorship (\$50)

_____ Hole & Table Sponsorship (\$125)

Prize Donation(s): _____

Registration form:

Foursome, \$100 per player

Player 1: Name, Address, Email

Player 2: Name, Address, Email

Player 3: Name, Address, Email

Player 4: Name, Address, Email

Lunch- non players, \$25 per person

Name(s) Address, Email _____

Payment Options: Checks may be made out to “Spina Bifida Association of NENY.” *Please send checks (or cash) and registration to:* **Nathaniel Crow, 5 St Stephens Ln E, Glenville, NY 12302**

Online registration and payment available by visiting: <https://ericcrowmemorialgolf.wixsite.com/ericcrow/copy-of-general-information>

On behalf of SBANENY and the countless individuals and families who rely on our programs every day, thank you for your consideration to be a part of the Eric N. E. Crow Memorial Golf Tournament!

SBANENY Updates

ADVOCACY

May 29, 2019 SBANENY was introduced on the New York State Assembly Floor by Assemblymember John McDonald III. A resolution was passed in both the New York State Senate and Assembly this year to officially recognize October as Spina Awareness Month.

View the introduction here: <https://nyassembly.gov/mem/?ad=108&sh=video&video=13574#videos>

Interested in advocacy? Join the committee and participate this fall when SBANENY meets with the NYS Executive Branch.



Spina Bifida Clinic being re-established at Albany Medical Center!

Spina Bifida Clinic to open this fall at Albany Medical Center.

After many years without a Spina Bifida clinic, providers at Albany Medical Center have worked to re-establish a more comprehensive care option for individuals and families living with Spina Bifida.

The Spina Bifida clinic will be based out of Albany Medical Center's developmental pediatric department. Individuals and families participating in clinic will be able to visit with various providers in one day including the neurosurgeon, urologist, and orthotist. The clinic will initially serve pediatric families.



Keep an eye out for more information!

Thank you to all of the medical providers who have continually dedicated and invested themselves in supporting the Spina Bifida community!

SCHOLARSHIPS

Madeline White receiving the 2019
Helen Merten's Educational
Scholarship sponsored by SBANENY.



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



SBANENY PROGRAMS

Art in Mind Paint Night , June 2019



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: \$8 per ticket. Pay via check or cash prior to the event. Pay online by visiting www.sbaneny.org and selecting the donate button. In the memo, type "ValleyCats"



6TH BIENNIAL EDUCATION DAY

SAVE THE DATE– MAY 30TH 2020

SUNY School of Public Health

University at Albany School of Public Health

1 University Place Rensselaer, NY

Wheelchair Partner Dance Workshop

Roll Call Wheelchair Dance will be returning this November to perform at the Dare to Dream gala on Saturday, November 23rd. The following morning, SBANENY & Roll Call will be hosting our second partner dance workshop for standing and seated partners. Save the date! More information on participating will be available in the next few months.



Equipment Exchange

DONATIONS AVAILABLE



Hand powered
outdoor ride-on toy



Walker



Bella's Bumba



2 boxes (4 packages in each box)
of briefs

EQUIPMENT REQUESTS

For loan or donation

- ◇ A small push ahead Walker (not a gait trainer) that would fit someone about 36" high.
- ◇ A stander
- ◇ A wheelchair with a seat between 8-11" that has a removable headrest, lateral supports and hip supports.

If you are interested in receiving or providing a donation, contact the SBANENY office!

National Spina Bifida Association Updates

Clinical Care Meeting

SBA hosted a Clinical Care Meeting in partnership with Lurie Children's Hospital from June 28-30 in Chicago, Illinois. Check out some of the live sessions on transitions, care coordination and community updates! <https://luriechildrens.mediasite.com/Mediasite/Catalog/catalogs/spina-bifida-critical-care-meeting-2019>

SB-You

The Next SB-You Webinar is taking place this July on Bowel Health. All SB-You materials and past webinars will be available at: <https://www.spinabifidaassociation.org/education/sb-you/>

Guidelines of Care

The Guidelines were developed to provide a road map of the best evidenced-based practices for Spina Bifida care from birth through adulthood. One hundred Spina Bifida experts from around the world spent three years developing these Guidelines that cover 24 topics ranging from bowel management to sexuality to physical activity and more. <https://www.spinabifidaassociation.org/guidelines/>

Save the date!

Fall Family Retreat at Double H Ranch

97 Hidden Valley Rd, Lake Luzerne, NY 12846

October 24-27. Thursday-Sunday



Dare to Dream

with SBANENY

Live & Silent Auction

Appetizers, Desserts & Live Entertainment by Fresh

November 23, 2019

6:00 to 10:00 PM

Honorary Chair, Jill Konopka WNYT

You Make a Difference Award Recipient: DJ Lou Roberts

Wheelchair Dance Performance

Join us as an attendee or consider an event sponsorship, honorary committee, or program advertisement!

For more information, contact SBANENY at 518-399-9151!

SBANENY Board of Directors



Are you interested in pursuing SBANENY's mission to enhance the lives of all affected by Spina Bifida? Consider joining 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. **Not sure what this entails? Contact SBANENY to learn more information!**

Recycle with SBANENY!



- Update SBANENY on your preferred contact method (mail, email, both!)
- Donate your used ink cartridges to the SBANENY office
- Clynk through Hannaford
 - 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.





**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

***ERIC CROW MEMORIAL GOLF
TOURNAMENT***

Saturday, September 28th
Eagle Crest, Clifton Park, NY

***DOUBLE H RANCH FALL FAMILY
RETREAT***

October 24-27
Lake Luzerne, NY

DARE TO DREAM

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

COMMITTEE MEETINGS

Dare to Dream— 8/13/19

**Audit, Finance and Investment—
8/5/19**

Education Day— August TBD

Fundraising & Marketing, 8/19/19

Board of Directors— 9/14/19

COMMITTEES TO JOIN

Advocacy

Audit, Finance and Investment

Board Development

Dare to Dream

Walk-N-Roll and/or 5K

FOR MORE INFO:

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Call us toll free: 855-722-6369

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

Website: sbaneny.org



facebook.com/sbaneny