



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 7th 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 20th. Are you registered? Do you have a team together? Do you want to know how to get involved? 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!

Did you know there is more that happens related to the SBANENY Walk-N-Roll than just the events of that day? Please be sure to check inside the newsletter to learn more about our Team Captain Kick-Off Event, corporate teams & corporate breakfasts, and snowflakes. Snowflakes in May you ask?! Read on to learn more about this initiative to raise Spina Bifida awareness.

I ask you to also read on to learn about the many ways that our staff, volunteers, and consumers from around the state are working to raise awareness. A team of advocates from SBANENY spent many hours early this year visiting elected representatives in Albany. These meetings involved educating about Spina Bifida and the needs of people living with the condition, as well as providing information about SBANENY and the extraordinary growth that we have experienced in outreach services in the past year.

In some contrast to our visits to Albany, inside you will also read about a science fair and a virtual fundraiser. How do these events help to raise awareness? See inside. Do you want to do an event in your community? Looking for ideas? We are happy to brainstorm with you to find a good match for you and your work, school, or community setting. Please contact our office to learn more.

I hope to see you at the Walk-N-Roll on May 20th!

Shelley Miller, 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 #71 APRIL 2017

Chair Letter

Team Captain Kick-Off Event

Walk-N-Roll & So Much More

Summer Sports & Upcoming Conferences

SBANENY Walk-N-Roll for Spina Bifida

Making a Difference

SBANENY News to Use

Upcoming Events

SBANENY BOARD

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Annmarie Fennicks

Margaret Huff

Gloria Zampini

Executive Director

Karen Wentworth

TEAM CAPTAIN'S KICK-OFF EVENT



Team Captains



TEAM CAPTAINS

SBANENY hosted our first ever Team Captain's Kick-Off Event on Saturday, April 8th at Buca di Beppo. The event was held for Team Captains & their guest who had a minimum of 5 team members registered and \$50 raised by April 1st.

Congratulations to the following team captains who qualified!

Bebi Ali– TEAM PIONEER
Alyson Bonhote– Zoe's Skaters
Bryan Darby– Hot Wheelz
Julia Duff–

SBANENY SHARES
Annmarie Fennicks–
Team Gazette
Amanda Ferguson–
Ranger Danger
Heather Horwedel–
Faith Trust and Pixie Dust
Jessica Ryder– Team Charlie

Thanks to everyone who attended!

This year's theme: **Snowflakes**

Spina Bifida is called a "Snowflake Condition" because no two people living with Spina Bifida are affected in the same way.

This Year's Contests and Awards

1. Team that raises the most money will receive the **Catering Experience** at this year's Walk-N-Roll *Winner is based upon total funds raised by May 18, 2017.
2. Team with the most spirit will kick off this year's event by **leading the Walk-N-Roll, carrying the SBANENY banner**
3. Individual who raises the most money will receive a **\$50 Visa gift card**



WALK-N-ROLL & SO MUCH MORE

NEW CORPORATE TEAMS

PIONEER BANK

TEAM PIONEER is one of our new corporate teams joining us at this year's event! THANK YOU for your support!

DAILY GAZETTE

The Daily Gazette is not only our presenting sponsor, but hosted SBANENY for a corporate breakfast! Thank you Team Gazette!



SCHENECTADY YMCA

This year the Schenectady YMCA allowed us to host a table at their site to provide information about the upcoming fundraiser and offer a wheelchair experience designed to raise awareness in the community. In addition, the Schenectady YMCA has registered as one of our new corporate teams!!!



IN THE COMMUNITY

Viaport Rotterdam

Viaport is hosting SBANENY on Saturday April 29 & Sunday April 30 from 11:00am– 3:00pm. Will you visit us? Tell your friends and visit the new aquarium while you are there!

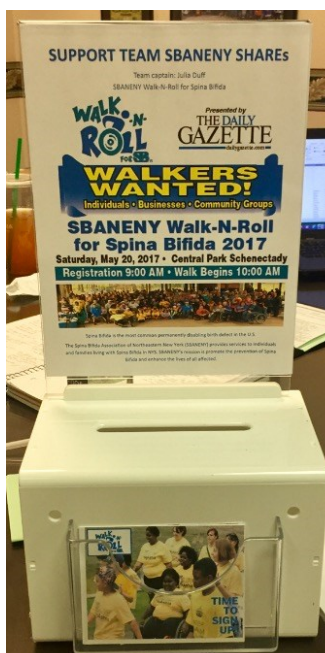
<http://www.viportrotterdam.com/>

DeMarco's Restaurant in Colonie

DeMarco's is a family owned Italian restaurant in Colonie. They are hosting our first donation canister! Thank you to DeMarco's for helping to raise Spina Bifida awareness and donations for our upcoming fundraiser!!

<https://www.facebook.com/demarcosalbany/>

<http://www.demarcoscolonie.com/>



READY FOR SUMMER



UPCOMING CONFERENCES

ADAPTIVE SUMMER SPORTS

Sunnyview Rehabilitation Hospital

- Rockwall Climbing- June 10, 9am
- Golf—June 16, 10am-12:30pm
- Fishing— June 21, 9:30-12:00pm
- Rowing—June 24, time TBD
- Sailing— August 8, noon-5:00pm
- Contact: 518-382-4576 / jennifer.battle@sphp.com

Helen Hayes Rehabilitation Hospital

- **May:** Golf, Climbing, Gardening
- **June:** Golf, Softball, Sailing, Fishing, Handcycling
- **July & August:** Handcycling
- Contact: Matthew Castelluccio
 - castellucciom@helenhayeshosp.org

Keep an eye out for these summer calendars!

Adaptive Sports Foundation

- www.adaptivesportsfoundation.org/

STRIDE Adaptive Sports

- www.stride.org/

SUMMER PROGRAMS

Double H Ranch

Starting in June, Double H hosts 6 day sessions for qualifying individuals (ages 6-16), alumni (17-21) and sibling sessions! Sessions are free for campers. Find more information by contacting Double H or visiting their website.

Julia Kusnier: jkusnier@doubleh.org

Phone: 518-696-5676 ext 263.

Website: www.doublehranch.org

Baltimore Education Day

Saturday May 6, 2017

8:00am-4:00pm

Kennedy Krieger Institute in Baltimore, MD

733 N Broadway

Baltimore, MD 21205

Lunch will be provided

Current agenda topics: Bowel program, managing incontinence, bladder and kidneys, tethered cord and blocked shunts, bones and joints, staying healthy, sexuality & fertility, and apps and aides helping in school and life.

Visit www.spinabifidaassociation.org for more information & to register.

Hydrocephalus Education Day— Greater New York

Saturday June 3, 2017

8:00am-3:00pm

NYU Langone Medical Center

Alumni Hall B (Main floor)

550 First Avenue

New York, NY 10016

The Hydrocephalus Association (HA) is hosting a free one-day event designed to deliver education, support and networking opportunities for individuals living with hydrocephalus and their caregivers located in the Greater New York area.

Visit <http://www.hydroassoc.org/education-days/> for more information and to register.



Presented by
**THE DAILY
GAZETTE**
dailygazette.com

WALKERS WANTED!

Individuals • Businesses • Community Groups

SBANENY Walk-N-Roll for Spina Bifida 2017

Saturday, May 20, 2017 • Central Park Schenectady

Registration 9:00 AM • Walk Begins 10:00 AM

Visit our website <http://sbaneny.org/>

- Register to walk
- Start your own team
- Virtual walkers welcome!

**To Register: Click on Walk-N-Roll
then click on Register Here**

**To Donate:
Click on General Donation**

Today you have the opportunity to make a difference!

BECOME A CORPORATE SPONSOR

**Go to <http://sbaneny.org/> click on Walk N Roll
then click on Become an Event Sponsor**

Titanium Sponsor



Gold Sponsors



Silver Sponsors

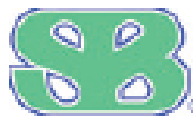


Brnze Sponsors



LEARNED | MEDICAL

**This event benefits
programs & services of**



**SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK**

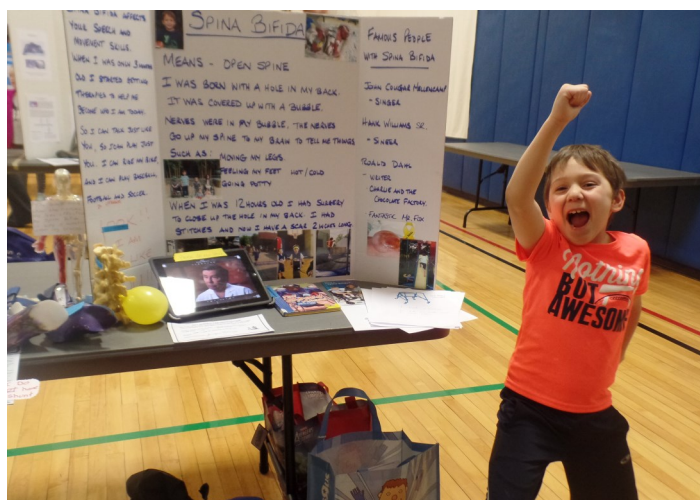
518-399-9151

Email: admin@sbaneny.org • Website: www.sbaneny.org

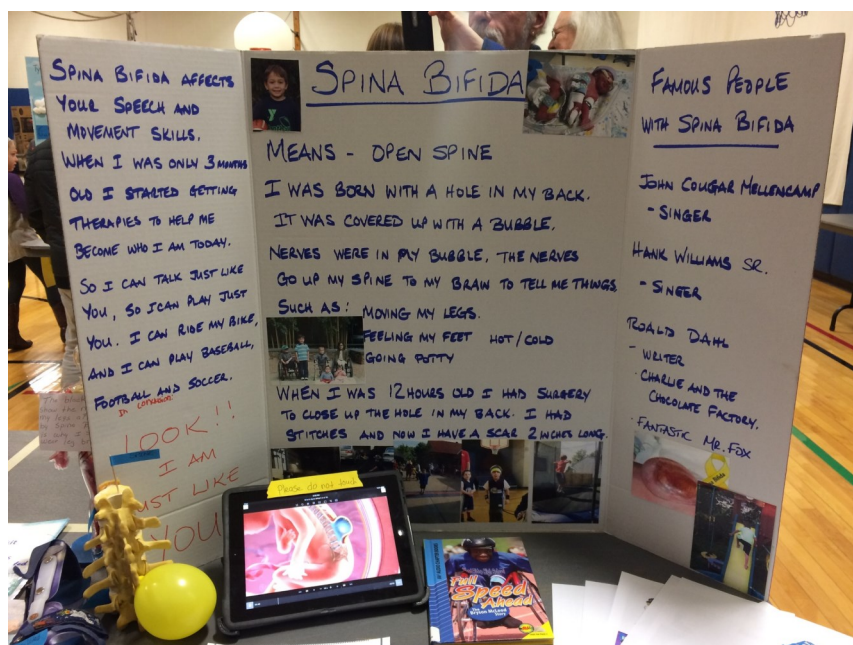
MAKING A DIFFERENCE



SCIENCE FAIR



Joshua is a 7 year old living with Spina Bifida in Central New York. For this year's science fair, Josh chose to make a display and provide information about living with Spina Bifida for his school. What a great way to raise awareness Joshua!



BELLA'S BUMBAS

Bella's Bumbas is a family run organization that is committed to building "Bumbo Wheelchairs" for children affected by Spina Bifida or any affliction that limits their mobility. It's named after Isabella Shorr (Bella), who was born in 2015 with a previously undetected diagnosis of Spina Bifida. It was a chair that her uncle built for her from plans found online that sparked the idea to create Bella's Bumbas.

Bella's Bumbas builds "Bumbo wheelchairs" and provides them at no cost to families, other than the cost of shipping. The seats are custom built to order in Webster, NY. They only ask that every family pass it on to another child after they've outgrown it!

For more information:

bellasbumbas@gmail.com

www.facebook.com/groups/bellasbumbas/

DELILAH'S FUNDRAISER

Delilah is a 9 year old going to school in the Mamaroneck Unified School District. This year, she is planning a fundraiser at her school for Spina Bifida. With the participation of her entire grade she will raise awareness about Spina Bifida and help support SBANENY! Keep an eye out on Facebook and in the next newsletter for pictures and follow up information on the outcome of her event!

Is there someone you know making a difference? Let us know!

Email: casemanager@sbaneny.org

Facebook: [facebook.com/Sbaneny](https://www.facebook.com/Sbaneny)

Phone: 518-399-9151

NEWS TO USE

SBANENY Raises Awareness for Spina Bifida with Elected Representatives

Earlier this year, our staff and a group of volunteers and consumers attended a series of meetings with key New York State representatives from the Senate and Assembly. This annual project, aimed at systems advocacy, secures meetings with key representatives in the legislature, Governor's office, and our federal representatives. The purpose of the project is to raise awareness about Spina Bifida and the needs of this community, provide an update about SBANENY, its activities, needs, and concerns, and to identify actions that representatives can take to support the SBANENY mission.

This activity also provides an opportunity to teach and practice advocacy to our youth, teens, and adults living with Spina Bifida. Participants have an opportunity to speak about their concerns related to Spina Bifida. They can address barriers in the community that cause challenges to their ability to maximize their potential, as well as needs in the community that are critical to improving the quality of life for this community.

Our SBANENY legislative visits took place in February and March. Visits with the Governor's office will be scheduled during the months of September and October.

Are you interested in self-advocacy, peer advocacy, and systems advocacy? Contact our office to learn more.

GRANT RESEARCH

SBANENY is looking for new sources of grant funding to continue expanding services and programming and to meet the needs of our growing community. We are seeking consumer input. If you or someone you know is aware of additional funding resources, we would love to hear about it! Contact the office and let us know.

DANCE ME SCHOOL

Shooting Stars Dance Class is for anyone with a disability who may have difficulty participating in a typical dance class. Whether you are a wheelchair user, living with a learning or other disability, all students are welcome!

126 Saratoga Rd.

Scotia/Glenville 12302

Studio # 518-357-3119

Please feel free to contact Miss Kathy with specific questions or if special arrangements need to be made: info@dancemeschool.com / 518-836-5102.

EQUIPMENT AVAILABLE

A family has reached out looking for a new home for the following equipment:

- **Convaid Cruiser stroller:** hot pink and black. 18" seat width, 170 Lbs. max. weight capacity.
- **Bath System:** Made by Duralife. The bath system includes a rolling shower chair and a white frame that sits in the tub and attaches to the chair. The chair is 18" wide, 40" long.
- **Vent/trach supplies**
- **Diapers** (adult size Medium-they run small)
- **Cases of Ensure**

Contact the office if you are interested!



**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, walker,
or donate at sbaneny.org.**

ABOUT SBANENY

Our purpose is

*Support
Health & Wellness
Awareness
Respect & Dignity
Empowerment*

UPCOMING EVENTS

***SBANENY WALK-N-ROLL FOR
SPINA BIFIDA &***

FAMILY & FRIENDS PICNIC

Saturday, May 20, 2017
Central Park, Schenectady

FALL FAMILY RETREAT

October 26—October 29 2017
Double H Ranch

***DARE TO DREAM WITH
SBANENY***

Saturday, November 18, 2017
Wolferts Roost Country Club

COMMITTEE MEETINGS

Board Development—5/8/17

**Fundraising & Marketing—
4/24/17**

Walk-N-Roll—5/2/17

**Dare to Dream with SBANENY—
5/9/17**

Education Day—6/2017

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 Conference

Young Families

Adult Group

NYC Metro Planning Group

Fundraising & Marketing

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

Website: sbaneny.org



facebook.com/sbaneny

WATCH FOR FLYERS!