



## SBANENY News to Use

### WELCOME LETTER

Happy New Year! SBANENY is excited and geared up for 2020. I hope you enjoy reading about all of the new opportunities for support and connections this year.

Save the date for SBANENY's winter and spring programs! SBANENY staff, individuals and families kick off our annual advocacy efforts on February 3rd with our SBANENY Legislative Day at the Legislative Office Building in Albany, NY. This is a great opportunity to raise awareness about Spina Bifida and work on self-advocacy skills! More information including our meeting schedule can be found inside this newsletter or by contacting the office.

SBANENY is also having a pool party this March for children and youth with Spina Bifida, their caregivers and siblings taking place at Goldfish Swim in Colonie, NY. This program is free and a great chance to get rid of those winter blues by swimming in a 90 degree pool with friends and families. RSVP by March 1st by emailing [casemanager@sbaneny.org](mailto:casemanager@sbaneny.org) to join us!

As always, SBANENY is hosting our Walk-N-Roll for Spina Bifida this May at Central Park in Schenectady, NY. 2020 is a special year as it is the 10 year anniversary of our Walk-N-Roll. Each year it is exciting to see the event grow and evolve with the addition of a morning 5K and all of the new friends, families, and businesses we connect with. Keep an eye out for the registration and fundraising website this February!

SBANENY is also sponsoring our 6th Biennial Education Day On May 30th-31st at the SUNY School of Public Health. Individuals living with Spina Bifida, family members and professionals in the community gather for education, networking and support. Check your mailbox and email for registration and scholarship information next month.

I want to take this time to thank the board members whose terms completed in 2020 including Lyndsi Holmes-Wickert, Kevin Chamberlain, Gloria Zampini and Michelle Miller. We are so grateful for the support you provided as board members and continue to as volunteers. SBANENY is excited to offer a warm welcome to Dave Wentworth, Jessica Ryder, Joe Slaninka, Paul Lukasiewicz and Jim Dunham who join the Board of Directors in 2020. Learn more about these caring professionals inside. For more information about Board membership reach out to the office!

Inside I hope you enjoy our informational resources and find greater details about any programs you may be interested in. I am always interested in hearing your feedback and sharing information about our programs, services, and volunteer opportunities. It is an honor to be the Executive Director of SBANENY and I look forward to all we will do together in 2020.

Julia Duff  
Executive Director

**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 #80 JANUARY 2020

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## SBANENY BOARD

**Chair:** Tracy Paige

**Vice Chair:** Jim Dunham

**Immediate Past Chair:**

Margaret Smith

**Treasurer:** Dave Wentworth

**Secretary:** Jessica Ryder

**Directors:**

Chris Darby-King

Robert Derrick

Helen Eggenberger

Peggy Felt

Paul Lukasiewicz

Jessica Ryder

Joe Slaninka

**Executive Director**

Julia Duff

*Thank you to our Dare to Dream presenting sponsor, Socha Plaza!*



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# SBANENY EVENTS CALENDAR

## SBANENY Legislative Day

- ♦ Monday February 3rd, 2020 8:30am-5:00pm.
- ♦ Monday February 10th, 2020 8:30am-5:00pm
- ♦ Legislative Office Building, Albany, NY

Join a group of SBANENY staff, individuals living with Spina Bifida, caregivers and friends of the Spina Bifida community in meetings with NYS Assembly and NYS Senate representatives where we raise awareness about Spina Bifida, promote the needs of individuals living with Spina Bifida across the lifespan, share individual experiences, and discuss the services that are provided by SBANENY to support individuals and families living with Spina Bifida.

Currently scheduled meetings:

**February 3rd:** Assembly: Woerner, Steck, McDonald III, Fahy, Walsh, Santabarbara. Senate: Breslin, Tedisco, Amedore

**February 10th:** Senator Carlucci (Chair of Mental Health and Developmental Disabilities), Senator Seward, Senator Rivera and Assemblyman Richard Gottfried (Health Committee Chairs)

If you want to attend or cannot attend but would like to submit a letter, please contact the office!

**Keep an eye out for an announcement regarding SBANENY being introduced on the NYS Assembly Floor in March 2020 to recognize October as Spina Bifida Awareness month in NYS! Contact the office to join us!**



## Pool Party!

- ♦ Sunday, March 8th 2020, 1:45- 4:00pm.
- ♦ Goldfish Swim, 145 Wolf Road, Colonie, NY 12205
- ♦ **Young families: Children and Youth with Spina Bifida ages 1-18.**
- ♦ This program is free.
- ♦ Bring your own swimsuit, towels, and change of clothes.
- ♦ RSVP by March 1st to join by contacting [casemanager@sbaneny.org](mailto:casemanager@sbaneny.org)



## Celebrating 10 years of the SBANENY Walk-N-Roll

Join us for the 10th Walk-N-Roll for Spina Bifida and 3rd 5K for Spina Bifida on May 16th at Central Park, Schenectady

**Sign up to walk, roll or race! (Website will be live by Feb 1).**

*Cannot attend?* Consider donating to support one of our family and friend teams and help SBANENY raise \$26,000 for programs and services!

### Registration Information:

7:15AM: 5k, \$20 (early bird pricing through April 30th)

9:00AM: Walk-N-Roll, \$5

Both: \$30

**There are opportunities to promote your business.** Contact Julia Duff to learn about our 2020 sponsor packages. If you are a not-for-profit, join us for free to provide information about your services to the anticipated 300 attendees!

For more information on participating please contact Julia Duff at 518-399-9151 or [admin@sbaneny.org](mailto:admin@sbaneny.org).



# SBANENY UPDATES

## 2020 SBANENY Education Day

### Empowerment through Information: Living with Spina Bifida

**When:** May 30th-31st 2020

**Where:** University at Albany School of Public Health  
1 University Place Rensselaer, NY 12144

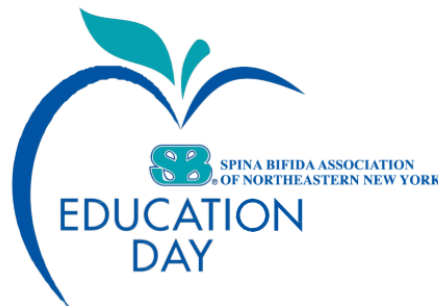
**Early bird pricing will be available!**

**Saturday, 8:00am-4:30pm**—Educational sessions on healthcare, financial planning, adaptive recreation and safety and relationships. Breakfast and lunch included. Sponsors and vendors will be in attendance providing information about their products and services.

**Saturday, 5:00pm-8:00pm**—Evening socials for adults living with Spina Bifida and parents of individuals with Spina Bifida at the Holiday Inn Express & Suites East Greenbush (Albany Skyline) . Dinner is included.

**Sunday, 8:00am-12:00pm**—Self-Care Exposition at the SUNY School of Public Health including a morning presentation on mental health and Spina Bifida, followed by opportunities to try out various forms of self-care including adaptive yoga, massage therapy, adaptive fitness, therapy dogs and more.

\* **Scholarships, registration, childcare and lodging information will be available in the near future. Questions? Contact Julia Duff at 518-399-9151 / [admin@sbaneny.org](mailto:admin@sbaneny.org)**



**SBANENY IN THE MEDIA-** Check out SBANENY on WNYT Channel 13 discussing Spina Bifida!

**10/20/19:** Jill Konopka interviews Julia Duff and Lyndsi Holmes-Wickert to discuss Spina Bifida and October Awareness Month: <https://wnyt.com/health/spina-bifida-awareness-month/5531016/>

**1/16/20:** Benita Zahn interviews Julia Duff about Spina Bifida: <https://wnyt.com/news/health-beat-spina-bifida/5601991/>

### Welcome to SBANENY's 2020 additions to the Board of Directors

**Jim Dunham:** Retired Elementary Principal and Special Education Teacher. Previous SBANENY Board Member and Chair, Chair of Policies and Procedures Committee, Governance Committee, Fundraising and Marketing Committee, Executive Director Search Committee. First experiences with Spina Bifida was with two students at Glen-Worden Elementary School, working as a staff and parent team with the Crow-Eggenbergers and Darby-Kings.

**Paul Lukasiewicz III:** 32 years old and live in Scotia with his fiancé and step daughter. He has his bachelor's degree in business administration from SUNY Delhi, is on the Walk-N-Roll committee and has worked for the Walt Disney World company in Orlando, FL.

**Jessica Ryder:** Resides in Mechanicville, NY with her husband, Tom and son, Charlie. Prior to becoming a parent she obtained her Bachelor of Science Degree in Business Management with a Human Resources concentration from Florida Gulf Coast University and worked as a receptionist for Capital Region Midwifery in Troy, NY. In 2016 Charlie was born and Jessica joined a direct sales company to help support her family while caring for Charlie and raising awareness for Spina Bifida and patient/family needs.

**Joe Slaninka:** Born with Spina Bifida and Hydrocephalus. 48 years old from Holbrook, Long Island. Works at the Henry Viscardi School as a disability advocate and wheelchair basketball coach. Married for 7 ½ years to Nicol.

**Dave Wentworth:** He is pleased to be joining the SBANENY board of directors as the incoming Treasurer. He recently retired from the General Electric Company, where he worked as a financial analyst and financial systems manager for 38 years. He was previously the Treasurer of the Scotia-Glenville All-Sports Booster Club and he currently volunteers for two programs for children with special needs. He is the husband of former SBANENY executive director, Karen Wentworth, so he has been involved with this organization as a volunteer for almost 20 years.



# Dare to Dream

with SBANENY



2019 You Make a Difference Award winner, Brother Lou Roberts. Thank you for making a difference through your annual support of the SBANENY Walk-N-Roll!

## HELP US SELECT OUR 2020 YOU MAKE A DIFFERENCE AWARD WINNER!

Who do you think makes a difference for the Spina Bifida community? Contact the office and let us know!



*Thank you to Jill Konopka from WNYT for being our Honorary Chair in 2019!*

*Thank you to our sponsors, donors, honorary committee persons and businesses, Board of Directors, Dare to Dream planning committee, and guests for making the night a success and contributing to the programs and services provided by SBANENY!*

★ Consider joining the fun and helping plan this event in 2020 by joining our committee!





# NEWS TO USE

## SBANENY FACEBOOK SUPPORT

Did you know SBANENY facilitates private groups on social media? Currently—SBANENY offers:

- ◆ Parents in downstate New York
- ◆ Adults living with Spina Bifida in/near NYC
- ◆ Double H Ranch— Follow up family support

For more information about these groups or to join one today—contact SBANENY! (518-399-9151/  
[admin@sbaneny.org](mailto:admin@sbaneny.org))

## SBA UPDATES

**Teal on the Hill** is taking place April 26th-28th, 2020 in Washington D.C. Join hundreds of members of the Spina Bifida community from across the U.S. as we create a sea of teal on Capitol Hill, advocating for issues such as continued funding for the Spina Bifida program at the CDC, disability rights, affordable and accessible health care, medical supplies and technologies. Your voice matters!  
<https://www.spinabifidaassociation.org/teal-on-the-hill/>

**SB-You Webinar:** How to Understand Your Insurance Coverage and Write an Appeal Letter is now available via SBA. To view this webinar and previous topics including fitness and bowel management, visit the link below:  
<https://www.spinabifidaassociation.org/?s=sb+you>

## PARENT TO PARENT NYS

Parent to Parent of NYS is offering a new initiative, Text4Caregivers which is a free text service that distributes timely and relevant self-care and stress-management support via text messaging. As a caregiver, you take care of others; this service exists to remind you to take care of you. To get started and receive free self-care text messages, fill out this online signup form:  
<https://platform.trumpia.com/onlineSignup/ddpctxt/text4caregivers>

## INTERNSHIP OPPORTUNITY

**Summer Transportation Internship Program:** The U.S. Department of Transportation's Federal Highway Administration is accepting applications for the 2020 Summer Transportation Internship Program for Diverse Groups (STIPDG). For more information:

- ◆ Internship period is from June 1<sup>st</sup>-August 7<sup>th</sup> 2020.
- ◆ The STIPDG provides college and university students with hands-on experience and training while working on current transportation-related topics and issues. The STIPDG is a paid internship program open to all qualified applicants but is designed to provide qualified women, persons with disabilities, and members of diverse groups with summer opportunities in transportation. **Applications are due February 1, 2020:**  
<https://www.fhwa.dot.gov/education/stipdg.cfm>

## FINANCIAL RESOURCES

### SBANENY Scholarships

#### FRANK BUCINO JR. MEMORIAL SCHOLARSHIP

The purpose of this scholarship is to award financial assistance to individuals with Spina Bifida of any age living in NYS to support:



**Conference Attendance:** Individuals and their immediate family's attendance at a national or regional Spina Bifida conference.

**Educational Scholarship:** Individuals with Spina Bifida who are pursuing higher education or technical training.

#### HELEN R. MERTENS EDUCATIONAL SCHOLARSHIP

The Helen R. Mertens Scholarship assists persons who have Spina Bifida living in Northeastern NY who are pursuing higher education, technical training, or driver's education.

\* **Applications are accepted on a rolling basis in 2020 and can be found at [www.sbaneny.org](http://www.sbaneny.org)**

## ADDITIONAL SCHOLARSHIPS & RESOURCES

**180 Medical:** offers scholarships to students with Spina Bifida attending a two-year, four-year, or graduate school program. <https://www.180medical.com/scholarships/>

**ABC Medical:** offers scholarships for adaptive sports, scholars and making a difference: <http://www.abc-med.com/scholarships>

**Gabriel's Foundation of Hope:** \$500 scholarships and grants for people with disabilities. <http://www.gabeshope.org/resources/scholarships/>

**The Hydrocephalus Association:** Provides financial assistance to young adults who live with hydrocephalus. <https://www.hydroassoc.org/scholarships/>

**J-Rob Foundation:** offers grants for adaptive sporting equipment to children with physical disabilities or challenges, 18 years or younger. <http://www.jrobfoundation.com>

**Jakes Help From Heaven:** supports individuals with multiple medical challenges and disabilities. Applicants must live within 100 miles of Saratoga, NY.  
[www.jakeshelpfromheaven.org/](http://www.jakeshelpfromheaven.org/)

**Building on Love, Inc.** provides temporary financial support to those who are struggling to keep up with their bills while undergoing treatment for a recent life-altering diagnosis. Pays funds towards bills, does not pay individuals. <https://buildingonlove.org/how-we-help/family-grant/>

**NY Able:** allows those with disabilities to save for qualified disability expenses without the risk of losing their benefits.  
<https://www.mynyable.org/>



## Program Updates

### Spina Bifida Family Weekend at Double H Ranch, October 24th-27th



### Adaptive Dance Workshop, November 24th



Thank you to everyone who joined us for the 2nd Adaptive Dance Workshop! A special thanks to Roll Call Wheelchair Dance, the Guiderland YMCA, and the Marjorie Rockwell Fund for the Disabled of The Community Foundation of the Greater Capital Region for making this all possible!

## GET INVOLVED WITH SBANENY IN 2020

As an organization that relies mainly on volunteers, participating on a SBANENY committee is a great way to give back this year. Check out opportunities to join the fun below!

Business and Finance

Conference

Dare to Dream

Direct Mail Campaign

Walk-N-Roll & 5K

Board Development

Contact the office for more information: 518-399-9151/ [admin@sbaneny.org](mailto:admin@sbaneny.org)



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*Memorial forms are available. Please contact our office.*



**Become a sponsor, plan to attend,  
or donate at [sbaneny.org](http://sbaneny.org).**

**ABOUT SBANENY**

*Our purpose is*

*Support*

*Health & Wellness*

*Awareness*

*Respect & Dignity*

*Empowerment*

**UPCOMING EVENTS**

***POOL PARTY***

Sunday March 8th, 2020  
Goldfish Swim School  
Colonie, NY

***WALK-N-ROLL & 5K***

May 16th, 2020  
Central Park, Schenectady, NY

***CONFERENCE***

May 30th-31st, 2020  
SUNY School of Public Health  
Rensselaer, NY

***COMMITTEE MEETINGS***

**Walk-N-Roll— 2/3/2020**

**Conference— 2/18/2020**

**Dare to Dream— 2/11/2020**

**Board of Directors— 3/8/2020**

***COMMITTEES TO JOIN***

Board Development

Business and Finance

Conference

Dare to Dream

Walk-N-Roll & 5K

Direct Mail Campaign

**FOR MORE INFO:**

Email: [admin@sbaneny.org](mailto:admin@sbaneny.org)

*Tel:* (518)399-9151

*Fax:* (518) 399-5639

Call us toll free: 855-722-6369

**VISIT OUR WEBSITE —  
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