



## SBANENY Newsletter

### WELCOME LETTER

Happy Spring!

We look forward to warmer weather and more outdoor activities. One of those is our 12th Annual Walk-N-Roll taking place again on Saturday, May 14th in Schenectady's Central Park and 2 "Hot Spot" locations downstate, including the Walkway Over the Hudson in Poughkeepsie and Eisenhower Park in Nassau County. Please join us in celebrating the Spina Bifida Community at any location by signing up today at [this link](#).

Over the last few months we have been very involved in advocating and raising awareness about Spina Bifida and SBANENY services. We were able to meet with over 25 representatives from the New York State Assembly and Senate. We've done that on an annual basis, to better inform our state representatives about what's needed by our consumers and our chapter. We thanked them for providing us with funding in the NYS Budget for the last two years and asked for them to consider ongoing funding. Stay tuned, because we are still trying to find out if we are in this year's budget.

SBANENY also represented all of New York State at the recent National SBA Teal on the Hill advocacy event requesting increased monies for CDC funding for the Spina Bifida program to improve research and healthcare outcomes for individuals living with Spina Bifida. It was a wonderful experience and opportunity to support national advocacy efforts.

We have also partnered with other SBA Chapters on a couple of programs including the 2nd Annual Strut & Stroll with SBA of Greater New England with over 200 registrants, featuring 8 models from New York State. The fantastic Fashion Show and roundtable with the contributing brands and designers can be found [here](#). I think that you will find it fun, inspiring, and informative!

We recently kicked off our 100 Mile Challenge – a wellness challenge with a twist, with an Education Day in partnership with SBA of Greater New England, Arizona, Iowa and North Texas. Over 100 registrants gained information about mental health, bowel and bladder health, physical activity and nutrition. A recording of all sessions can be found at our YouTube Channel as well.

You can see that we are actively supporting the Spina Bifida Community in a variety of ways. If you'd like to find out more or perhaps join us for future activities go to our website—[www.sbaneny.org](http://www.sbaneny.org). Thank you very much for your support!

Jim Dunham, Chair

SBANENY 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.

ISSUE #89  
APRIL 2022

### WELCOME LETTER

WALK-N-ROLL FOR  
SPINA BIFIDA  
SBANENY PARTNERS  
WITH BYRAM  
SBANENY PROGRAMS &  
EVENTS  
WALK-N-ROLL  
SPONSORS  
SBA UPDATES  
NEWS TO USE

### SBANENY BOARD

**Chair:** Jim Dunham  
**Chair Elect:** Michelle Miller  
**Immediate Past Chair:**  
Margaret Smith  
**Treasurer:** Dave Wentworth  
**Secretary:** Jessica Ryder  
**Directors:**  
Kevin Chamberlain  
Chris Darby-King  
Robert Derrick  
Crysal Hoey  
Valerie Joseph  
Paul Lukasiewicz, III  
Jessica Ryder  
Diane Skibinski  
Joe Slaninka  
Andrew White

**Executive Director**  
Julia Duff



PRESENTED BY BYRAM HEALTHCARE

# 12th ANNUAL WALK-N-ROLL FOR SPINA BIFIDA

ALL PROCEEDS BENEFIT THE PROGRAMS AND SERVICES OF:



**SB** SPINA BIFIDA ASSOCIATION  
OF NORTHEASTERN NEW YORK



## SATURDAY MAY 14TH

**Central Park, Schenectady, NY from 10:00am-2:00pm**

**The Walk-N-Roll is a free event featuring DJ Lou Roberts, raffles, vendors, contests, prizes, snacks, Say Cheez foodtruck, and games!**

**REGISTER AT [WWW.SBANENY.ORG](http://WWW.SBANENY.ORG)!**

**Help the Spina Bifida Association of Northeastern New York (SBANENY) build a better and brighter future for all those impacted by Spina Bifida!**

*SBANENY is a nonprofit serving individuals and families living with Spina Bifida.*

*Your donations benefit those we serve and are tax deductible!*

**Contact Julia Duff at 518-399-9151 or [admin@sbaneny.org](mailto:admin@sbaneny.org) with questions!**

### Thank you to our sponsors!





# NEW WALK-N-ROLL LOCATIONS IN 2022!

CONSIDER VISITING A "HOT SPOT" IN POUGHKEEPSIE OR LONG ISLAND  
TO CONNECT WITH OTHER FRIENDS IN THE SPINA BIFIDA COMMUNITY!

## POUGHKEEPSIE WALK-N-ROLL

WALKWAY OVER THE HUDSON

10:00 AM TO 12:00 PM ON MAY 14TH, 2022!

61 PARKER AVE, POUGHKEEPSIE, NY

BROUGHT TO YOU BY:



**MidHudson  
Regional Hospital**  
Westchester Medical Center Health Network



SPINA BIFIDA ASSOCIATION  
OF NORTHEASTERN NEW YORK



Information on available services will be provided  
We encourage you to bring your own picnic and enjoy the scenery!

CONTACT: JULIA DUFF  
ADMIN@SBANENY.ORG  
518-399-9151

## LONG ISLAND WALK-N-ROLL

### When & Where:

- Saturday 5/14/2022
- 9am-1pm Eisenhower Park
  - Parking field 4

### What can you expect?

- Raffles and family friendly activities
- Beverage by Williston Park Beverage
- Food provided by Williston Park Rotary Club and Albertson Fire Department
- Live music



For more information,  
email Julia at  
admin@sbaneny.org

Thank you to our 2022 partners!



## BYRAM HEALTHCARE IS PROUD TO SPONSOR THE 2022 WALK-N-ROLL FOR SPINA BIFIDA®



### WITH BYRAM, YOU HAVE CHOICE. CHOOSE THE CATHETER THAT'S RIGHT FOR YOU.

Byram delivers high quality catheter supplies directly to your home,  
empowering you to live your life to the fullest potential.

#### HERE'S WHAT TO EXPECT FROM BYRAM

- Insurance coverage verification and billing
- Timely delivery of your supplies to your home
- Collaboration with your doctor and insurance to receive high quality affordable care
- We will communicate with you when your order ships and provide tracking information
- Byram will contact you if there are any issues with your order

#### MORE INFORMATION

Scan the QR Codes with your smartphone to learn about why Byram is the Right Choice for Your Urological Supplies or visit:  
[byramhealthcare.com/spina-bifida-ne-ny](https://byramhealthcare.com/spina-bifida-ne-ny)



 SCAN ME



[byramhealthcare.com](https://byramhealthcare.com)   

Wound Care | Diabetes | Urology | Ostomy | Incontinence | Enteral Nutrition | Breast Pumps

©2022 Byram Healthcare Centers, Inc. All rights reserved.



# SBANENY Updates & Programs

## March 17th, 2nd Annual Strut & Stroll: Fashion For All

The 2nd Annual Strut and Stroll in collaboration with the Spina Bifida Association of Greater New England took place last month featuring models with Spina Bifida from both chapters. The fashion show premiere was followed by a roundtable where models and designers got to answer questions about the future of adaptive fashion. A recording of the show can be watched [HERE](#). Enjoy some pictures of our models below!



## April 2nd- May 14th, 100 Mile Challenge

Since April 2nd, SBANENY has been going 100 miles for Spina Bifida! Alongside four other Spina Bifida Association chapters across the country, we are logging miles as we work towards our wellness goals. If you would like to join the challenge visit the registration page [HERE](#). Participation is free with a wide array of wellness opportunities!

- **Kick-Off Virtual Education Day**—SBANENY co-hosted an Education Day with the partnering chapters to kick off the 100 Mile Challenge. Sessions topics include mental health, staying active, bowel and bladder health, and nutrition. You can access all the recordings by clicking [HERE](#).
- **Programs and Workshops in May:** Join us as we round out our 100 Mile Challenge with virtual programs leading up to our annual Walk-N-Roll on May 14th! These programs target changing specific wellness habits to enhance your overall fitness and well-being.
  - **Chair Yoga with Leni Ferner:** May 1st, 12-1PM. Register [HERE](#)
  - **Value Wheels Webinar:** May 3rd, 5:30-6:30PM. Register [HERE](#)
  - **Progress Check-In:** May 5th, 8-9PM. Register [HERE](#)
  - **Forest Bathing– Virtual Experience with Suzanne Bartlett Hackenmiller:** May 9th, 8-9PM. Register [HERE](#)
  - **Forest Bathing Part Two with Dr. Hackenmiller:** May 11th, 8-9PM. Register [HERE](#)
  - **Wrap-Up Party:** May 16th, 8-9PM. Celebrate your accomplishments with our 100 Mile Challengers! Register [HERE](#)

*Keep up to date with all of our programming!*

*You can find our program archive [HERE](#) and see upcoming programs [HERE](#)!*

---

## April 29th—May 1st, NY Metro Abilities Expo

**New Jersey Convention & Expo Center, 97 Sunfield Avenue, Edison, NJ 08837**

SBANENY will be attending the 2022 NY Metro Abilities Expo, sharing a table with our friends from The Spina Bifida Resource Network and Spina Bifida Association Of The Delaware Valley.

Schedule:

- 4/29: 11:00am-5:00pm, 4/30: 11:00am-5:00pm, 5/1: 11:00am-4:00pm

Learn more and sign up to attend for free [HERE](#).

Reimbursement scholarships are available to offset the costs of travel and lodge. To learn more, click [HERE](#).



# SBANENY Updates & Programs

## April 20, 2022, Capital Region Today with Ann Parillo

Thank you Ann Parillo for having Executive Director Julia Duff on Capital Region Today to discuss Spina Bifida, SBANENY, and our upcoming Walk-N-Roll presented by [Byram Healthcare!](#) Watch the full interview [HERE](#).



## Spina Bifida Healthcare Provider Survey

SBANENY is seeking to expand our database of medical care providers who work with individuals living with Spina Bifida. We are asking for your help in updating and adding to this database by sharing information on your care providers as well as any information you have on other providers and specialists that are serving the Spina Bifida community. Find the survey [HERE](#)!

- On Friday, May 13th, SBANENY will be attending the Spina Bifida pediatric and adult clinics at Albany Med! To learn more about clinical care at Albany Med, click [HERE](#).

## Congratulations to Conlee & Bryan!

This April, SBANENY wished Conlee and Bryan good luck as they transitioned to new employment opportunities!

*Thank you both so much for your years of support pursuing our mission!*



## Spina Bifida Association of Northeastern New York takes on Citi Field for Spina Bifiday Day!



**SUNDAY July 3rd, 1:40pm @ CITI FIELD**

**(41 Seaver Way, Queens, NY 11368)**

**TEXAS RANGERS VS. NY METS**

FOR INFORMATION  
AND QUESTIONS,  
CONTACT: JULIA DUFF  
SBANENY EXECUTIVE  
DIRECTOR

518-399-9151  
[ADMIN@SBANENY.ORG](mailto:ADMIN@SBANENY.ORG)



Join SBANENY and friends for a day at the ballpark! SBANENY will be featured on the scoreboard, receive the NY Mets Spirit Award, and be announced at the stadium! Tickets are \$40.00 per person. Seats are field level/left field and accessible seating is available! Attendees responsible for their own transportation and meals.

**PURCHASE YOURS TODAY AT [WWW.SBANENY.ORG](http://WWW.SBANENY.ORG)**



# Thank you to our Walk-N-Roll Sponsors!

*Thank you so much Rivers Casino & Resort Schenectady for selecting SBANENY as the charity of choice this past February. Rivers Casino & Resort was able to raise over \$4,400 for SBANENY programs and services in just 28 days!*

*Thank you for helping us build a better and brighter future for all those impacted by Spina Bifida!*



*You can learn more about Rivers at our 2022 Walk-N-Roll at Central Park, in Schenectady, NY.*

## Thank you to our Walk-N-Roll Sponsors!



SPINA BIFIDA ASSOCIATION  
OF NORTHEASTERN NEW YORK

THE DAILY  
GAZETTE



# National Spina Bifida Association Updates

**Clinical Care Meeting:** The Spina Bifida Clinical Care Meeting is an opportunity for healthcare professionals serving the Spina Bifida community to network, partner, and collaborate. CME's and CEU's will be available. Attendees will learn about SBA's Collaborative Care Network, the latest research, SBA priorities, and care processes of importance to people living with Spina Bifida. The event will consist of plenary sessions that all participants will attend, followed by a series of breakout sessions that attendees can choose from.

When & Where: June 3rd—June 5th, Boston Children's Hospital in Boston, Massachusetts

- [VIEW THE AGENDA](#)
- [REGISTER TO ATTEND](#)
- *SBANENY is offering reimbursement scholarships to offset costs of registration, travel and lodge. You can find more information on the available scholarships [HERE](#).*



## National Survey Results: The COVID-19 Vaccine

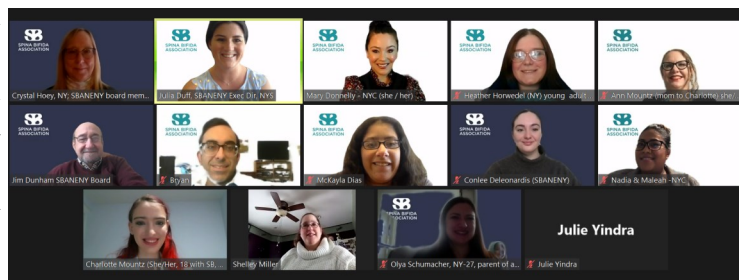
The National Spina Bifida Association recently conducted a survey about Spina Bifida and the COVID-19 vaccine. The feedback received will go a long way in helping advocate for the Spina Bifida community. To see the results click [HERE](#). Find more information and the answers to your questions from SBA's Medical Director [HERE](#).

## Teal on the Hill—Advocacy Follow-Up

Nearly 150 people from across the country, including people living with Spina Bifida, their parents, caregivers, and medical professionals, participated in 86 meetings with U.S. House and Senate staff members as part of the Spina Bifida Association's annual "Teal on the Hill."

Advocates shared their experiences living with Spina Bifida and requested an increase of \$4 million a year for the National Spina Bifida program at the U.S. Centers for Disease Control and Prevention (CDC). (*Read the entire article [HERE](#).)* Part of the National Spina Bifida program at the CDC is the National Spina Bifida Patient Registry (NSBPR). SBA's Professional Advisory Council advocated for the establishment of the NSBPR at CDC, to collect the scientific data needed to evaluate existing medical services for spina bifida patients. Established in 2008, the Patient Registry provides the framework for a systematic approach to improving the quality of care received at spina bifida clinics nationwide.

- To learn more about the Patient Registry, click [HERE](#).
- All publications from the NSBPR can be found [HERE](#).



## Chapter Awards

The National Spina Bifida Association Chapter Awards are now open for nominations! Awards you can submit nominations for include: Innovative Programming, Outstanding Program for Adults, Outstanding Program for Children, Volunteer of the Year, and Outstanding Awareness Campaign. Submit your nominations [HERE](#) by June 3rd and keep an eye out for a celebration ceremony on Wednesday June 29th!



# NEWS TO USE

## SCHOLARSHIPS

### SBANENY Scholarships

Did you know SBANENY offers three scholarships to support individuals and families with Spina Bifida?

- **Helen R. Mertens:** Scholarships for individuals with Spina Bifida pursuing higher education, technical training, or drivers education.
- **Frank Bucino Jr. Memorial:** Scholarships for people with Spina Bifida attending a national or regional Spina Bifida Conference OR in the pursuit of education or technical training.
- **Technology and Related Supports:** Scholarships for people and families living with Spina Bifida to provide or improve access to virtual opportunities as a result of the COVID-19 pandemic.

Click [HERE](#) to learn more and apply in 2022!

## ACCESS

### Adidas Pushing For Greater Inclusion Of Athletes With Disabilities

- Adidas is calling on marathons to set aside bib number 321-a figure associated with Down syndrome for neurodivergent runners and one of the country's biggest races is already on board. Read [this article](#) to see how Adidas is pushing for changes in the athletic industry.

### National Public Health Week in NYS

- In observance of National Public Health Week, The NYS Department of Health (DOH) Highlights the importance of an accessible state for all New Yorkers. The DOH commits to advancing health solutions for New York residents living with disabilities or mobility limitations through advocacy and the creation of specialized programs. Read the full press release [HERE](#).

### NY to Make Absentee Ballots More Accessible for Voters with Disabilities

- A federal court approved the terms of a settlement agreement that requires the NYS Board of Elections to create a statewide remote mail-in system so that voters who are blind, or have other print disabilities, can read and mark their ballots independently. Read the full article [HERE](#).

## EQUIPMENT

### The National Disability Institute (NDI) Spotlight on Permobil: Assistive Technology Including Standing Wheelchairs

- Thursday, April 28th, 2022: 12:00-1:00 p.m. ET
- This webinar will discuss the medical and functional importance of standing, review the tried-and-true qualities of the F5 Corpus VS, and discuss the latest updates including a new group 3 Medicare coding option!
- Register [HERE](#).

## HOUSING

### Biden Administration Expanding Medicaid Program That Helps People Leave Institutions

- The Centers for Medicare and Medicaid Services said that it will make available over \$110 million to expand the Money Follows the Person program which gives states extra funds to provide employment, housing and other services to help people transition from nursing homes and other institutions to homes in the community. Read the full article [HERE](#).

## EMPLOYMENT

### Schenectady County Connects: Job Trainings

- Schenectady County Connect is offering virtual workshops on resume development, employment skills, services, career fairs, and more! Check out the May classes [HERE](#).

### Employment First Community of Practice

- A webinar on "Employment Networks" (EN) is happening on April 27th from 3:00-4:00 p.m. A panel of experts will discuss Employment Networks and provide suggestions and perspectives from the administrative, state, and provider level on Employment Networks' benefits for Competitive Integrated Employment opportunities. Register [HERE](#).



# NEWS TO USE

## RESEARCH

### Survey for people with I/DD seeking Health Care

- The Association of University Centers on Disabilities (AUCD) and Community Catalyst are holding a focus group to learn about the experiences of people with intellectual and developmental disabilities (I/DD) when getting health care. They know that visits to the doctor are not always great, and want to make them better. Hearing about your experiences will help educate doctors, nurses, and therapists about what they can do to make your health care visits better. Click [HERE](#) to take the survey.

### Help Us Find the Causes of Spina Bifida!

- The Gleeson Lab at UC San Diego is working to set up an international registry of patients with meningomyelocele and fund new studies investigating how folic acid reduces the risk of Spina Bifida. This study is supported by a National Institute of Health (NIH) awarded grant from the NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development. Take the survey [HERE](#).

## PROGRAM OPPORTUNITIES

### The Disability EmpowHer Network

- This is a national organization that facilitates different programmatic experiences for women and girls with disabilities. They are currently accepting applications for their Disability EmpowHer Camp—a year long opportunity for teens girls ages 13-18.
- You can view the application [HERE](#). (Deadline to apply is April 24th!) Learn more about their organization [HERE](#).

### National Spina Bifida Education Day for Young Adults and their Families

- Transition Throughout Life - Living with a Chronic Condition, April 30, 2022
- The presentations will address medical, educational, and social topics related to growing up with Spina Bifida, and will present information for teens and young adults with Spina Bifida and their families.
- There will also be time for Q&A with the speakers and panelists at the conclusion of each presentation.
- \$25.00 per household—Purchase your ticket [HERE](#)!

## DISASTER PREPAREDNESS

### The Dialogue

- A new issue of The Dialogue from the Substance Abuse and Mental Health Services Administration (SAMHSA) Disaster Technical Assistance Center (DTAC) explores ways to ensure inclusion of people with disabilities and other functional and access needs in all phases of disaster preparedness, response, and recovery. Read the issue [HERE](#).

## SEXUAL EDUCATION TRAININGS FOR PEOPLE WITH I/DD: LEARN TO LEAD

### For Teaching Teams Made Up of a Self-Advocate and a Professional

- May 10-11, 9:00am-4:30pm @ CFDS, 314 South Manning Blvd. Albany, NY 12208
- In this 2-day in-person training, teams of self-advocates and professionals will learn how to lead sexuality education classes for people with I/DD.
- This training serves Region 3 counties: Albany, Columbia, Dutchess, Fulton, Greene, Montgomery, Orange, Putnam, Rensselaer, Rockland, Saratoga, Schenectady, Schoharie, Sullivan, Ulster, Warren, Washington, Westchester
- Register [HERE](#).

### For Teaching Teams Made Up of a Person with I/DD and a Professional

- June 2-3, 9:00am-4:30pm @ SANYS, 1021 Broadway Street Buffalo, NY 14212
- In this 2-day training, you and your team member will learn how to lead sexuality education classes for people with I/DD in your community. Your team should include one self-advocate (a person with I/DD) and one professional.
- This training serves Region 1 counties: Allegany, Chemung, Cattaraugus, Chautaugua, Erie, Genesee, Livingston, Monroe, Niagara, Ontario, Orleans, Schuyler, Seneca, Steuben, Wayne, Wyoming, Yates. Additional trainings will be held in other regions.
- Register [HERE](#).

***Find all of our previous E-News and Newsletters available on the SBANENY website [HERE](#)!***





## SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK

### ABOUT SBANENY

***Mission:** To build a better and bright future for all those impacted by Spina Bifida.*

***Our purpose is***

***Support***

***Health & Wellness***

***Awareness***

***Respect & Dignity***

***Empowerment***

---

### UPCOMING EVENTS!

*Adult Group*

April 26, 2022

*Walk-N-Roll for Spina Bifida*

May 14, 2022

*Spina Bifida Day at Citi Field*

July 3, 2022



---

### JOIN THE TEAM!

If you are interested in offering your support and expertise to the Spina Bifida community, contact the Spina Bifida Association of Northeastern New York to learn more about our Board of Directors, Professional Advisory Council, or one of our volunteer committees!

#### *COMMITTEE MEETINGS*

**Governance**—May 4, 2022

**Development**—May 18, 2022

**Dare to Dream**— May 11, 2022

**Board of Directors**— May 21, 2022

#### *COMMITTEES TO JOIN*

Conference

Development

Dare to Dream

Direct Mail Campaign

---

### 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.*