



Hello!

Happy spring! I hope you have been able to enjoy the recent warmer weather. SBANYS is excited to have a busy spring with activities and programs.

For the 2<sup>nd</sup> year in a row we are hosting two separate Walk-N-Roll events. The first is May 13<sup>th</sup> at Eisenhower Park in East Meadow and the second one is on May 21<sup>st</sup> at Central Park in Schenectady. Both events include raffles, merchandise, food, contests/prizes, music and games. Both events will also have Disney princesses! It's not too late to sign up and join us at one or both events! It is best to register for the Walk-N-Roll prior to the day of the event(s). See our website for the link to register. I look forward to seeing everyone!

SBANYS is also busy with different programs including the Spina Bifida Book Club, Wellness Initiative, and Self-Advocacy Training Program: Tools to Take Control of Your Life. All programs are provided virtually and at no cost.

While you are enjoying the warmer weather of spring, you may see us at different events such as the NY Metro Abilities Expo on May 5<sup>th</sup> through May 7<sup>th</sup> and the Albany Tulip Festival on May 13<sup>th</sup> and 14<sup>th</sup> in Washington Park. When you see us, come by and say hello!

SBANYS invites you to join one of our Fundraising & Marketing/Development and Dare to Dream Gala committees. We are looking for fun, creative members who want to support and make a difference in the lives of individuals living with Spina Bifida and their circle of supports. Please contact the office for more information.

All my best,  
Michelle Miller  
Board Chair

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## ISSUE #93 APRIL 2023

WALK-N-ROLL FOR  
SPINA BIFIDA  
BOTTLE & CAN DRIVE  
SBANYS PROGRAMS  
UPCOMING EVENTS  
WALK-N-ROLL  
SPONSORS  
VOLUNTEERS  
GET INVOLVED

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# ANNUAL WALK-N-ROLL FOR SPINA BIFIDA

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AND BRIGHTER FUTURE FOR ALL THOSE IMPACTED BY SPINA BIFIDA!



**SATURDAY,**

**MAY 13TH, 2023**

EISENHOWER PARK, EAST  
MEADOW, NY FROM 10AM-2PM



**SUNDAY,**

**MAY 21ST, 2023**

CENTRAL PARK, SCHENECTADY,  
NY FROM 10AM-2PM

THE WALK-N-ROLL IS A FREE EVENT FEATURING MUSIC, FRIENDS & FAMILY PICNIC,  
CONTESTS & PRIZES, MERCHANDISE, RAFFLES, GAMES & ACTIVITIES, & SPONSOR &  
VENDOR TABLES THROUGHOUT THE ENTIRE DAY!

**DAY OF REGISTRATION OPENS AT 9:00AM.**

**REGISTER HERE: [WWW.SBANYS.ORG](http://WWW.SBANYS.ORG)**

CONTACT [ADMIN@SBANYS.ORG](mailto:ADMIN@SBANYS.ORG) OR 518-399-9151  
FOR MORE INFORMATION!

*SBANYS is a nonprofit serving individuals and families living with Spina Bifida.  
Your donations benefit those we serve and are tax deductible!*



# SBANYS Programs

## Tools to Take Control of Your Life—Virtual Self-Advocacy Training Program

Through knowledge, community, and training, you will have the tools to take control of your life!

The Tools to Take Control of Your Life Virtual Self-Advocacy Training Program for individuals with disabilities ages 14+ is just getting started! You can still sign up for our free future trainings covering boundaries, confidence, communication, rights/resources, housing, employment and healthcare.



Sign up here: <https://forms.gle/qneYtPCgJtqzrrhp6>

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## The Wellness Initiative

A nationwide program providing wellness opportunities for people living with Spina Bifida and their family members to help reach their goals and form healthy habits.

Capital Region Families - join us for our in-person events as an extension of this initiative!

- **Inclusive Zumba with Bring on the Spectrum**

- **Where:** Bring on the Spectrum, 71 Fuller Road, Albany
- **When:** Sunday, April 23rd at 11:30 AM
- **Who:** This program is for individuals living with Spina Bifida (ages 16+) and caregivers. This event will be followed by lunch at a restaurant in Stuyvesant Plaza. The program is free but you are responsible for your own lunch.



- Reserve your spot for this event: <https://forms.gle/xPyLaEidui8k5qL7>

- **St. Christopher Fitness Adaptive Workout**

- **Where:** 22 Clifton Country Rd, Suite 32, Clifton Park
- **When:** June 3rd from 2:30-3:30 PM



- **Who:** This program is for individuals living with Spina Bifida (ages 18+). Individuals will receive a tour, workout, and Q&A with SCF owners. This event will be followed by lunch in Clifton Park Plaza. The program is free but you are responsible for your own lunch.

Reserve your spot for this event: <https://forms.gle/dGqcZdeiwB69nKBH7>

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## ADAPTED WHEELCHAIR BASKETBALL TOURNAMENT FOR SPINA BIFIDA AWARENESS

**Saturday, April 22, 2023, 9:00am-2:00pm, Henry Viscardi School**

Come enjoy a day of competitive wheelchair basketball. SBANYS will also be raising awareness about attending and donating to the upcoming Long Island Walk-N-Roll. For more information contact Joe Slaninka, 516-368-2271 / frankenbif@hotmail.com.



As a part of our upcoming Walk-N-Roll, at Central Park in Schenectady, NY SBANYS is accepting bottles and cans for collection!

# BOTTLE & CAN DRIVE

Clynk through Hannaford is a program where you can donate your recyclable bottles and cans to an organization of your choice. On Sunday, May 21st we will be accepting bags of bottles and cans from the community and to donate to SBANYS through Clynk!



Sunday, May 21st,  
10:00am-1:00pm  
Central Park- Schenectady, NY,  
500 Iroquois Path Schenectady,  
NY 12309

For more information: 518-399-9151/[admin@sbanys.org](mailto:admin@sbanys.org)



# SBANYS Programs

## SBANYS Paid Internship Program

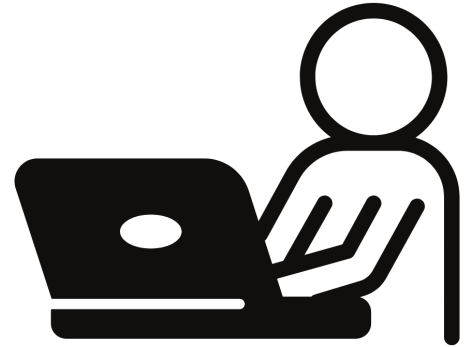
### We are recruiting!

The goal of this internship is to expand upon job skills and work-related experience and enhance awareness of personal values, skills, and needs to promote gaining meaningful employment. The internship is a paid, part-time, and temporary position. When possible, the internship will take place in-person at the SBANYS office. No prior work experience is required to apply.

Interns may be required to complete an employment assessment to determine if being accompanied by an employment specialist/job coach through an alternate agency is necessary.

All potential interns will be required to submit a completed application and return it to SBANYS via mail: 133 Saratoga Rd, Professional Building, Office 4, Scotia, NY 12302 or email: [admin@sbanys.org](mailto:admin@sbanys.org) as well as be interviewed by the SBANYS Executive Director.

For more information, please visit the link: <http://sbanys.org/chapter-programs/financial-scholarships/>



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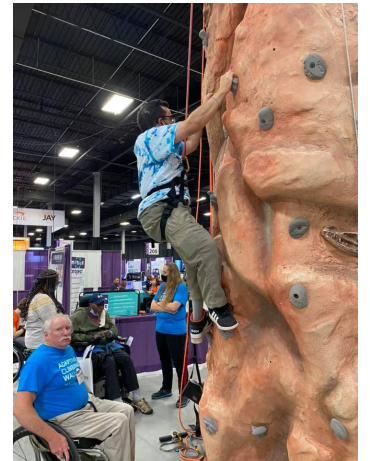
## NY Metro Abilities Expo

### Friday May 5th—Sunday May 7th, New Jersey Convention & Expo Center

The Abilities Expo brings you thousands of game-changing tech, products and services. Regardless of the type and level of your disability, the event strives to provide the resources you need. Attend one day or the full weekend and meet with hundreds of vendors and attend interactive workshops and events.

If you need financial assistance for travel and lodging, visit <http://sbanys.org/chapter-programs/financial-scholarships/> to apply for the Frank Bucino Jr. Scholarship available on our website.

Register to attend here: <https://www.abilities.com/newyork/>



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## Albany Tulip Festival

### Saturday May 13th, 2023—Sunday May 14th—2023

### Volunteers needed!

We are seeking volunteers to host the SBANYS table at the Albany Tulip Festival! Tulip Festival takes place at the Albany Washington Park from **May 13th-14th**. Volunteer shifts take place in pairs and cover 2-3 hours each day. If this is something you would be interested in volunteering for, please email [admin@sbanys.org](mailto:admin@sbanys.org) or call the office at (518) 399-9151!



# SBANYS Programs

## Parent/Caregiver Support Group

This group was created to provide a safe space to discuss the day-to-day experiences of caregivers, navigating systems, share information, provide connections and vent!

If you are a parent or caregiver of someone living with Spina Bifida (of any age) and are looking for group support, here is your opportunity. **We will be hosting our first meeting on Wednesday, April 26th, at 6:30pm via Zoom followed by another meeting on Friday, May 19th at 12:00pm via Zoom.**

**Email [admin@sbany.org](mailto:admin@sbany.org) to receive the link to join us at one/both meetings!**



## Adult Group

SBANYS adult group brings people from across the country to meet virtually in a safe space for all of us to discuss the daily obstacles and successes people with Spina Bifida experience. Adult group consists of focused discussions, open chat, and game nights! Adult Group takes place on the 4th Tuesday of every month.

**Next group is Tuesday, April 25th via Zoom at 5:30pm.** If you have not already registered to join, do so here:

<https://us02web.zoom.us/join/8679111111?pwd=ZUJlYkRlMjVkdDZkdzFScEo0dDZldz09>

## Book Club

**Book Club is a national program** connecting adults and caregivers to each other through reading. Each cohort meets every other night in the evenings. Save the date and register for our upcoming Book Clubs!

- Adults, **May 11th**: Carissa's Law by Misty Boyd via Zoom at 7:30pm EST. *Author will be joining!*
- Caregivers, **June 8th**: Smart but Scattered by Peg Dawson & Richard Guare via Zoom at 7:30pm EST
- Register to receive invites to book club here: <https://forms.gle/R5v7weuJ6TyDvRSM6>
- To receive invites to only specific club meetings, you must email the host that month.

## Youth Book Club coming this summer!

The Spina Bifida Association, its chapters and other Spina Bifida service organizations are offering our first kid/teen book club this summer. There will be three groups: 5-9 years, 10-13 and 14-18. While you are encouraged to read whatever books you choose, reading lists will be provided. The reading period is **June 19th—July 26th** with the book club discussion held on **July 27th** via Zoom. Kids 5-9 will meet at noon EST. The 10-13 age group will meet at 1:30 EST, and the 14–18-year teens will meet at 3 p.m. EST. Parents must submit this form to enter their child or teen and provide contact information. Siblings are invited to participate too! <https://forms.gle/cNJpCc1phQRNV1c49>



## UPCOMING EVENTS

### **Traveling the Road to OPWDD Eligibility & How Self-Direction Can Give You the Tools for a Fuller Life, Thursday, April 20th 10 am – 11:30**

Learn how to navigate the winding road of OPWDD eligibility. Find out how you can gain greater control of services through self-direction and the fine points of using self-direction once OPWDD eligible.

Register to attend here: [https://us06web.zoom.us/webinar/register/WN\\_Rqh3auxOSP24Ad3tpCz0yQ](https://us06web.zoom.us/webinar/register/WN_Rqh3auxOSP24Ad3tpCz0yQ)

### **Runway of Dreams @ Marist College Presents:**

#### **An Adaptive Fashion Show: Inclusion for EveryBODY, Friday, April 21, 2023 6:00 pm EST**

Join Runway of Dreams for a memorable evening of inclusion and empowerment at Marist College's first annual Adaptive Fashion Show taking place at Steel Plant Studios Winter Garden Café at Marist College (11 Beck Pl, Poughkeepsie, NY 12601). This adaptive Fashion Show will feature models with disabilities from the Tri State area and will be rocking adaptive fashion from Zappos. Admission is free.

For more information:

<https://runwayofdreams.ticketspice.com/2023-marist-adaptive-fashion-show>

### **CREATE: Assistive Technology Competition**

CREATE challenges student engineers to develop an assistive technology innovation for workers with disabilities to remove barriers from the workplace within a NYSID Member Agency. Students from five colleges and universities across the state participate in a day-long symposium:

**Monday, April 24, 2022**

Empire State Plaza, Meeting Room 6

Time: 10:00 a.m. – 1:00 p.m.

\*Open to the public\*

Join in discovering the newest technologies from tomorrow's engineers!

### **2023 Disability Policy Seminar, April 24th & 27th**

This year's Disability Policy Seminar promises a program that will equip you with the information, skills, and confidence to be a strong advocate for disability rights. The seminar will kick off with a virtual all day training session on **April 24<sup>th</sup>** on topics such as; bills being introduced to congress, how disability programs will be funded, any risks to funding, and how the debt ceiling impacts people with IDD! Then you have the opportunity to meet with a Congress member to put your skills to action on **April 27<sup>th</sup>** via virtual appointments. Registration is required, sign up here: <https://disabilitypolicyseminar.org/registration-information/>

### **Summer Youth Employment Program**

Schenectady County residents ages 14-24 are eligible to apply for the Summer Youth Employment Program from 7/3/2023-8/11/2023. The deadline to apply for this program will be **April 21<sup>st</sup>**. This is an opportunity for adolescents and young adults to learn foundational skills that are key to employment, earn and manage money, and networking skills! Apply here: <https://drive.google.com/file/d/1yWW5dB19W5KAurpvbMWTT6hQO6A0IIh/view>

Register here: <https://us3.campaign-archive.com/?u=9cb8efcbe3cc381d9742fc411&id=511b89d1be>

### **Disabled Women Make History (and Art):**

Disability EmpowHER Network is partnering with The Toledo Museum of Art to celebrate the creative women in the community. This event will take place in the Glass Pavilion of the Toledo Museum of Art on **Saturday, June 24<sup>th</sup> 2023 from 6-8 PM**. Women living with a disability are encouraged to submit their artwork for consideration to be displayed at this unique event. Learn more and submit your art here:

<https://docs.google.com/forms/d/e/1FAIpQLSfILUlagosRyn3PwRy6UWxArmKQeSdr7BQ-DGErHE9LeQeAKw/viewform>

***Links provided in this newsletter can be requested by emailing [admin@sbany.org](mailto:admin@sbany.org)***

# VOLUNTEERS NEEDED!



SPINA BIFIDA  
ASSOCIATION  
OF NEW YORK  
STATE

## Direct Mail Campaign

- Help draft and distribute the annual direct mail campaign via mail, email, newsletter and social media

## Walk-N-Roll

- Plan and coordinate the annual Walk-N-Roll for Spina Bifida assisting with event planning including catering, volunteers, decorations, marketing, promotional materials, contests and prizes. Meetings are monthly via Zoom for 1 hour.

## Dare to Dream

- Join a fun team of dedicated individuals who work year round to plan our annual gala, Dare to Dream. Participation includes assisting with marketing, auction items, entertainment, sponsors, venue and more. Meetings are monthly via Zoom for 60-90 minutes.

## Development

- Assist with developing and implementing the fundraising and marketing needs of SBANYS to support programs and services. Meetings are every other month via Zoom for 1 hour.

## Governance

- Review SBANYS policies and procedures, address conflicts of interest, and assist with developing the Board of Directors. Meetings are monthly via Zoom for 1 hour.



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SPINA BIFIDA ASSOCIATION  
OF NEW YORK STATE

## ABOUT SBANYS

**Contact:** [admin@sbany.org](mailto:admin@sbany.org) / 518-399-9151 / 133 Saratoga Road, Suite 4, Scotia, NY 12302

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

**Our purpose is**

**S**upport

**H**ealth & Wellness

**A**wareness

**R**espect & Dignity

**E**mpowerment

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## UPCOMING EVENTS!

*Zumba, Albany, NY*

4/23/2023

*Adult Group, Zoom*

4/25/2023

*Walk-N-Roll, Schenectady & East Meadow, NY*

5/13/23 & 5/21/23



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## JOIN THE TEAM!

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

### COMMITTEE MEETINGS

**Development** —TBD

**Walk-N-Roll**—April 26, 2023

**Dare to Dream** —April 19, 2023

**Governance**— April 18, 2023

**Board of Directors**— May 8, 2023

### COMMITTEES TO JOIN

Conference

Development

Dare to Dream

Direct Mail Campaign

Walk-N-Roll

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## ESTATE PLANNING, MEMORIALS & HONORARIUMS

*Have you considered including SBANYS in your estate plans?*

*You may also want to consider honoring or memorializing a friend or a loved one with a gift to SBANYS. Memorial forms are available. Please contact our office.*