



Hello,

I am happy to introduce myself as the 2024 Chairperson of the Spina Bifida Association of New York State's (SBANYS) Board of Directors! I hope you enjoyed the holiday season! Here's to 2024 being a banner year for SBANYS!

Now that we are in a new year, a new era, SBANYS will undergo some strategy changes, all while keeping our mission the same, bettering the lives of those impacted by Spina Bifida through our many programs and services, advocacy and education.

The NYS Spina Bifida Advocacy Day is February 6, 2024 in Albany, in person. I hope you can join us in advocating for those living with Spina Bifida and let our representatives know the importance of our statewide organization. If you cannot join us in person, please consider voicing your support for our ask. You can find more information inside this newsletter.

We are currently accepting applications for councilmembers for our brand new Regional Advisory Council, Caregiver Advisory Council, and Adult Advisory Council. We are also continuing our committee recruitment efforts for Walk-N-Roll, Fundraising and Marketing, Dare to Dream, and Advocacy. Volunteerism is very important for any organization to survive and thrive. SBANYS is no different. We are always looking for enthusiastic, creative individuals to assist in our efforts. Spread the word in your circle of friends, family and colleagues.

Save the date! Our Annual Walk-N-Roll events are being planned as we speak for the weekend of May 18th (Eisenhower Park) & May 19th (Schenectady Central Park). Online registration will be available in February.

I am very proud of the work we are doing, and I am excited to see where 2024 takes us. Thank you for your hard work and dedication! Let's Go SBANYS!

Sincerely,

Joe Slaninka, Board Chair

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## ISSUE #96 JANUARY 2024

SBANYS UPDATES  
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## SBANYS BOARD

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# SBANYS Updates

## Meet the new members of our team!

### Kathleen Watt

Kathleen started in July, 2023 as an MSW intern from the SUNY Albany School of Social Welfare and is now our full-time Individual Family Service Provider (IFSP) responsible for providing individual and family services, education outreach, and programming for the Spina Bifida (SB) community. To contact Kathleen directly please call the office at 518-399-9151 or email her at [Kathleen.Watt@sbanys.org](mailto:Kathleen.Watt@sbanys.org)



### Francis Lee-Ciano

Hello! My name is Francis and I am a new intern for SBANYS! I am so excited to be an intern for this amazing organization. I love to do artistic things such as makeup and collages in my room. I also am very motivated in all the things I do so I always try to do my best.



### David Oliver

My name is David Oliver, I am from Rhinebeck New York and currently studying at Siena College. I'm now halfway through my third year studying as a Marketing major here at Siena, which has been an amazing experience. It excites me to know I will be advocating for such an important community, while also gaining experience in a business environment. I look forward to working with the whole team!



## WALK-N-ROLL FOR SPINA BIFIDA



EISENHOWER PARK,  
EAST MEADOW, NY  
SATURDAY, MAY 18,  
2024



CENTRAL PARK,  
SCHENECTADY, NY  
SUNDAY, MAY 19,  
2024

# SAVE THE DATE

# SBANYS Advocacy

**If you are ready to be a part of a better and brighter future for all those impacted by Spina Bifida in New York State, our 2024 Advocacy Event is for you!**

Each year, SBANYS staff and advocates visit with NYS Senators and Assemblymembers to communicate updates about the policy and budget needs of the Spina Bifida and greater disability community. SBANYS also requests NYS's continued financial support for statewide programs and services. **We invite you to join us on Tuesday, February 6th, for Spina Bifida Advocacy Day!**

## RAISE YOUR VOICE



### Where:

- Meetings are scheduled in person at the Legislative Office Building in Albany, NY. Some virtual meeting opportunities are available during the month of February.

### Who:

- **Who are we meeting with?** Assembly & Senate targets include regional representatives and the Committee Chairs of Disability, Health, Mental Health, Ways and Means/Finance, Majority Leaders, Presidents and Speakers.
- *Request the schedule and meeting materials by emailing [admin@sbanys.org](mailto:admin@sbanys.org).*

### Our Budget Ask:

- We are requesting that SBANYS be included in the NYS budget for \$125,000 in 2024 to support our annual growth in requests for services. NYS funding would aid our efforts to host programs and improve service delivery for consumers across the state and lifespan. As the sole affiliate chapter in our state, without any restrictive eligibility requirements, NYS funding is vital to advance services and supports for those impacted by Spina Bifida in NYS.

### How can you get involved?

- **Register to join us** on February 6th, 2024: <https://forms.gle/c1dDqLkFBFLgDx9o9>
- **Contact your representative** within minutes with our customized email templates. We highly encourage you to tailor your message and share information about how life with Spina Bifida impacts you/your family and how SBANYS services can make a difference. <https://www.votervoice.net/SBAA/Campaigns/100279/Respond>.
- **Opt-in to receive advocacy text messages** containing meeting updates, budget developments, and important bills that affect our community. Text "ADVOCACY" to 518-320-7571 to opt-in today!
- **Submit a video testimonial** on why SBANYS deserves to receive continued funding from NYS in order to support, educate, and advocate on behalf of the Spina Bifida community. To submit a video testimony, contact [admin@sbanys.org](mailto:admin@sbanys.org).

# SBANYS Programs

## Adult Group

Join our next adult group meeting via Zoom on February 27, 2024 at 6:00pm. During the February group, WheelChariot will be presenting on their web platform where users can rate and review public locations on their accessibility. Register to attend here: <https://us02web.zoom.us/join/zoom/register/tZErdOurqz8oGNRQrAhgW1rgMxYBLHm-XqYQ>.

## SBANYS Kick-Off Event (1/22/24) Recording:

<https://www.youtube.com/watch?v=GUNuWfMslU8>.

# National SBA Programs

## Community Information Session – Exploring Weight Management

Weight management is complex but critical to understand. Abnormal weight status has a profound impact on overall health and is associated with secondary health conditions. When co-occurring with Spina Bifida, carrying excess weight further limits one's independence and ability to self-manage health. This presentation will provide a broad overview of weight management and the role of weight-related behaviors such as nutrition and physical activity. **This virtual session will address the unique considerations associated with Spina Bifida on January 25th, at 7 pm.** Register to attend or receive the recording here: [https://give.sbaa.org/event/exploring-weight-management-and-weight-related-behaviors/e549928?c\\_src=website&c\\_src2=eventlisting](https://give.sbaa.org/event/exploring-weight-management-and-weight-related-behaviors/e549928?c_src=website&c_src2=eventlisting)

## 2024 Teal on the Hill

Teal on the Hill is an annual event that brings members of the Spina Bifida community together from across the U.S. to advocate for issues such as continued funding for the National Spina Bifida Program at the Centers for Disease Control & Prevention (CDC); disability rights; and affordable and accessible health care, medical supplies, and technologies. Be a part of the movement!

**When:** Sunday, February 25, 2024 - Tuesday, February 27, 2024

**Where:** Virtual, via Zoom

**Registration:** ranges from \$25.00-\$100.00—register by February 9th.

**Scholarships:** Email [advocate@sbaa.org](mailto:advocate@sbaa.org) if you cannot afford to attend but would like to. You can also apply for a SBANYS scholarship at this link: <https://forms.gle/h2MLkvScfDqhRgcq6>.

**For more information—schedule, FAQs, and resources click here:**

<https://www.eventcreate.com/e/2024-teal-on-the-hill>





# Committee Recruitment

## NEW COMMITTEE RECRUITMENT!

### Advocacy Committee

**Definition:** Individuals impacted by Spina Bifida or individuals interested in local, state, and federal legislative advocacy and policy.

**Term:** One year term with virtual monthly meetings through April and then bimonthly meetings.

**Responsibilities:**

- Help provide insight into the advocacy priorities of SBANYS.
- Participate in the planning of SBANYS legislative day and advocacy appointments.
- Set the legislative objectives and goals for SBANYS.
- Steward new advocates and advocacy groups to assist with SBANYS advocacy efforts.



### Fundraising & Marketing Committee

**Definition:** Individuals who are dedicated and interested in assisting SBANYS in achieving our fundraising and marketing goals.

**Term:** One year term with bi-monthly virtual meetings.

**Responsibilities:**

- Sharing suggestions and strategies for enhancing current fundraising events.
- Brainstorming new fundraising and marketing ideas.
- Helping address the development goals of the Executive Director and SBANYS Board of Directors including corporate partner development, donor relationships, etc.
- Assisting with establishing regional fundraising opportunities.
- Communicating about strategies and providing feedback via email.



***We are also continuing to recruit volunteers to assist on our Board Governance, Business & Finance, Walk-N-Roll and Dare to Dream committees! For more information, email [admin@sbanys.org](mailto:admin@sbanys.org)!***

# Advisory Council Recruitment

**As part of SBANY'S 2024 Operating Plan, we have launched three new advisory councils to help guide our services across the state and lifespan!**

## Regional Advisory Council

**Definition:** A group of individuals who live, work, recreate, and/or have an interest in the region that can help address the local needs and wants of the Spina Bifida community.

**Term:** One year term with quarterly virtual meetings.

### Responsibilities:

- Provide insight into the regional needs of your local community.
- Share relevant resources for consumers and professionals who contact SBANY'S from your region.
- Provide local expertise and connections to help facilitate regional programs and events.
- Share available resources that may benefit individuals who live in other regions.

**Application:** <https://forms.gle/g2yFoX4tcGxUk2zMA>

## Caregiver Advisory Council

**Definition:** A group of parents of children with Spina Bifida who share insight, support, and resources related to the needs of parents of children with Spina Bifida and their families.

**Term:** One year term with quarterly virtual meetings.

### Responsibilities:

- Provide insight into the experiences of caregiving for a child with Spina Bifida.
- Help determine the program and service needs of parents of children with Spina Bifida.
- Collaborate with other parents who have children with Spina Bifida.
- Share experiences and resources that could benefit other families.

**Application:** <https://forms.gle/q1TaFpa4W4V1GJZx9>

## Adult Advisory Council

**Definition:** A group of adults (21+) living with Spina Bifida who share insight, support, and resources related to the needs of living with Spina Bifida

**Term:** One year term with quarterly meetings

### Responsibilities:

- Provide insight into the experiences of living with Spina Bifida.
- Help determine the program and service needs for adults with Spina Bifida.
- Collaborate with other adults who live with Spina Bifida.
- Share experiences and resources that could benefit the Spina Bifida community.

**Application:** <https://forms.gle/ssr8TnAA77Q37C9F9>

# News to Use

## Program Opportunities

- **Lifeplan CCO Webinars: Member and Family Forums**
  - Emergency Preparedness, Thursday, 2/1, from 12-1pm.
  - Prepare for a Loved Ones Care After You're Gone, Thursday, 2/15, from 12-1pm.
  - **Register:** <https://lifeplanccony.com/upcoming-member-and-family-forum/>
- **Northwestern Mutual Special Needs Planning Workshops**
  - How to Develop a Life Plan for Your Child with Disabilities, Tuesday, 2/13 at 5:00pm.
  - [https://us06web.zoom.us/webinar/register/5416922182712/WN\\_hZqk2-ARRDeRsZXALVXXzw#/registration](https://us06web.zoom.us/webinar/register/5416922182712/WN_hZqk2-ARRDeRsZXALVXXzw#/registration)
  - ABLE Accounts vs Special Needs Trusts: An In-Depth Discussion, Wednesday, 2/14 T 2:00pm.
  - [https://us06web.zoom.us/webinar/register/9316922181664/WN\\_STrUXuXQQayZ3QXifFtHQQ#/registration](https://us06web.zoom.us/webinar/register/9316922181664/WN_STrUXuXQQayZ3QXifFtHQQ#/registration)

## Language Support

- **Learn English for Free with Cell-Ed:** The NYS Office for New Americans is offering the opportunity to learn English for free with Cell-Ed, a mobile-friendly tool that facilitates English and Spanish language learning, offering skills development for both life and work. Accessible 24/7, Cell-Ed is free, secure, and doesn't require a smartphone or internet connection; it's even available through dial-in and WhatsApp. Download Cell-Ed today and enter code 1788 to get started! For more information, please contact [NewAmericans@dos.ny.gov](mailto:NewAmericans@dos.ny.gov).

## Equipment

- **An individual in Bayside Queens is looking to donate** Convatec #401544 pouches, #401575 wafers cut too a 1 1/8 size opening, and a box of large diapers. Contact the office if you are interested.

## Adaptive Fashion

- **Vollbrecht Adaptive Counseling** has developed a 10 course training covering various topics related to adaptive fashion. To learn more, visit: <https://www.udemy.com/user/tracy-vollbrecht/>.
- **Billy Footwear** has partnered with SBANYS to offer a 15% donation to our organization every time you make a purchase using our custom link. Check it out! [billyfootwear.com/?ref=SBANYS](http://billyfootwear.com/?ref=SBANYS).

## Resources

- **The *Exceptional Parent, People, Physician, Patient Magazine*** has come out with a new issue talking about how to navigate the resources needed for children with disabilities, diagnostics for rare disorders, how families with disabilities can find support, tips for parents that have children with dyslexia, and more! To read the magazine click <https://www.epmagazine.com/>

## Health

- **The Disability and Health Program** is pleased to announce the Commissioner's Medical Grand Rounds on "Working with People with Intellectual and/or Developmental Disabilities Across Health Care Settings," is now available for viewing. This webinar explores healthcare delivery highlighting gaps in services faced by individuals with I/DD. View the webinar here: [https://www.health.ny.gov/commissioner/grand\\_rounds/working\\_with\\_people\\_with\\_idd/](https://www.health.ny.gov/commissioner/grand_rounds/working_with_people_with_idd/)

## Survey

- **Help Congressman Tonko identify the services that benefit you the most!** Congressman Tonko is looking for individuals to fill out a constituents service survey to let his team know what is important to your wellbeing. [https://tonko.house.gov/forms/form/?ID=24&utm\\_campaign=900-405](https://tonko.house.gov/forms/form/?ID=24&utm_campaign=900-405)

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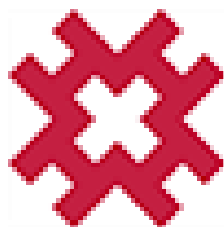
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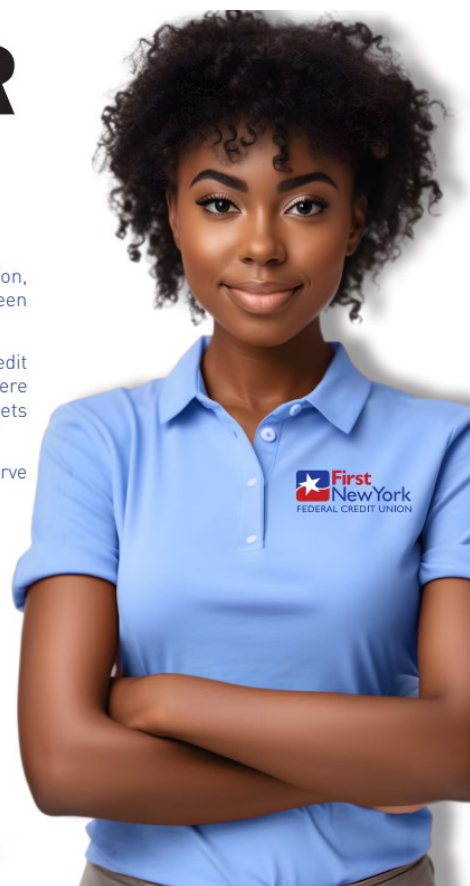


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Edward J. Johnson, Jr.,  
InfoEd Global, President





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!

*Adult Group*

January 23, 2024

*Advocacy Day*

February 6, 2024

*Walk-N-Roll*

May 18 & 19, 2024



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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!

## COMMITTEES TO JOIN

- Development
- Dare to Dream
- Direct Mail Campaign
- Walk-N-Roll

## 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.