



SPINA BIFIDA ASSOCIATION OF NEW YORK STATE



Hello and Happy New Year!

I hope your 2022 year wrapped up by spending time with family and friends during the holiday season. SBANYS rounded out the year with the 11th Annual Dare to Dream Gala which was our biggest fundraiser to date. Thank you to all who attended either in person or virtually, bid on silent and live auction items, donated, sponsored or volunteered!

As we look to 2023, SBANYS continues our advocacy journey on the state and federal level. To go along with our advocacy efforts, SBANYS has been awarded a grant through the DDPC for a Self-Advocacy Training Program for individuals living with Spina Bifida ages 14+. Be on the lookout for further information from our staff at SBANYS.

This May, we will be traveling again to New Jersey to attend the NY Metro Abilities Expo to raise awareness about Spina Bifida and SBANYS services the weekend of 5/5/23-5/7/23. Additionally, plans are in the works for our Annual Walk-N-Rolls which will once again be held at Central Park in Schenectady, NY on Sunday 5/21/23 **and** at Eisenhower Park in East Meadow, NY on 5/13/23. There will be the walk and roll, picnic, raffles, and activities for all ages and abilities.

We are always looking for more volunteers and committee members. If you want to get more involved in SBANYS, please contact the office at 518-399-9151.

Sincerely,
Michelle Miller
Board Chair

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ISSUE #92 JANUARY 2023

DARE TO DREAM GALA
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DARE TO DREAM GALA

160 virtual
and live
attendees

\$42,000
raised for
SBANYS

80
baskets
won

Congratulations to our Dare to Dream awardees!

- **SUNY School of Social Welfare,
You Make a Difference Award**
- **Orlo Hulett Sr., Volunteer of the
Year**
- **Ed Wilcenski, Esq. Honorary Chair**

FEATURED PERFORMERS

**Jennie Angel,
Official Member of
The Academy of
Country Music**

**Maddie Gallagher,
Teenager living
with Spina Bifida**

Thank you to the 2022 Dare to Dream Planning Committee!

**Abby Mundell
Ann Humiston
Carla Perrone
Crystal Hoey
Jessica Ryder
Judy Fillmore
Kevin Chamberlain
Karen Wentworth
Michelle Miller
Diane Skibinski
Peggy Smith**



SBANYS Updates

SBANYS RECOGNITIONS



**Capital Region Chamber
Excellence in Local Impact**



**Times Union
The Big \$100,000 Give Away**



**UFCW Local "The One"
Charity Golf Classic Charity**



SBANYS's Celebrating our 30-Year Anniversary!

2023 Calendars are available for **\$30.00**. The calendar features individuals and families living with Spina Bifida. All proceeds (after shipping) will help raise funds for SBANYS programs and services. Purchases can be made online at www.sbanys.org or by contacting the office: 518-399-9151.

SAVE THE DATES!

WALK-N-ROLL'S FOR SPINA BIFIDA



2023 Locations:

**Eisenhower Park,
East Meadow, NY
Saturday, May 13, 2023**

**Central Park,
Schenectady, NY
Sunday, May 21, 2023**

SBANYS Programs

PROGRAMS YOU MAY HAVE MISSED!

Financial Planning Series

Recordings: [Budgeting Basics](#), [Financial Planning Basics](#), [Wills, Trusts and Power of Attorneys](#), [Public Benefits and Financial Literacy: What you need to know!](#)

UPCOMING PROGRAMS

Adult Group

Join our next adult group meeting via Zoom on January 24th at 5:30pm EST. Register to attend [HERE](#). Save the date! Our February and March groups are 2/28 and 3/28.



- **Adult Group Survey**

- SBANYS staff April Pilczuk created the following questionnaire to try to determine what topics are the most important to cover during group sessions. By responding, it will allow SBANYS to provide topics and a structure for groups that will allow participants to get the most value out of attending. Please share your thoughts for Adult Group here: <https://forms.gle/VZs8GnRSVEXUt5wQ6>

Book Club

This October SBANYS and chapters across the country launched two separate book clubs for adults living with Spina Bifida and parents/caregivers of individuals with Spina Bifida. Book clubs take place via Zoom every other month on Thursday evenings at 4:30pm PDT/7:30pm EDT. Sign up and find the upcoming dates and authors for book club [HERE](#).

Our next book club is taking place on the evening of February 9th, 2023 and is for caregivers of a person with Spina Bifida!

- Author: Ketrina Hazell
- Book: [Special Education to College The Ketrina Story: Breaking Those Glass Ceilings](#)

Self-Advocacy Training Program

SBANYS has received a grant from the New York State Developmental Disabilities Planning Council to provide a 1-year Self-Advocacy Training Program for individuals 14 years old+ living with a disability. More details will be distributed this February.

In the meantime, we are seeking volunteers to assist with the planning and implementation of the program. You can still participate even if you help plan! What does participating on the planning committee entail?

- Identifying disability service agencies in NYS to invite to participate in the program
- Surveying the community to identify the priority topics to be included in self-advocacy training for the Spina Bifida and IDD community
- Developing a curriculum and recruiting speakers
- Evaluating the effectiveness of the program

To participate, email admin@sbanys.org!

Advocacy

New York State Advocacy with SBANYS

When:

- Monday 1/30/23 and 2/6/23 & Tuesday 1/31/23 and 2/7/23

Where:

- Most** meetings take place via Zoom. Some meetings are scheduled in person at the Legislative Office Building in Albany, NY on Monday 1/30/23.

Who:

- NEW IN 2023:** Regional Advocacy Meetings
 - SBANYS is recruiting consumer advocates to participate in meetings with representatives from their region (WNY, CNY, Capital Region/Hudson Valley, Taconic Region, Northern NY, and NYC & Long Island). **Do you want to meet with your representative? All you have to do is email admin@sbany.org and we will schedule it!**
 - Find your Assemblymember [HERE](#). Find your Senator [HERE](#).
- 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@sbany.org*

SBANYS advocacy presents a unique opportunity for you to share your story without having to travel! What we know is that the NYS Assembly and Senate representatives want to hear YOUR VOICE! If you are available, please consider attending the scheduled meetings to share your story, raise awareness, and make a difference.



National Advocacy with SBA, SBANYS, and fellow advocates across the country

When: February 26th-28th

Where: Virtual, via Zoom

Who: Consumers who want to advocate with federal representatives in New York State

What: Teal on the Hill is an annual event that brings hundreds of 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 and medical supplies.

Registration: ranges from \$25.00-\$100.00—register [HERE](#). Email communications@sbaa.org if you cannot afford to attend but would like to. **Scholarships are available through SBANYS.**

For more information—schedule, FAQs, and resources click [THIS LINK](#).



JOIN A COMMITTEE!



Advocacy

- Participate in meetings with representatives, identifying agenda priorities and following up with your representative!

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.

News to Use

Health

Protect your kidneys & skin this winter! With the holiday season coming to a close, you may have experienced abnormally high levels of stress. As we know, stress and anxiety can lead to urinary problems. Additionally, winter weather can negatively impact your skin integrity affecting circulation and dryness. Check out the resources below to proactively address your health this winter season.

- [Urological Updates](#)
- [Stop Sepsis](#)
- [Byram's Urology Health Newsletter](#)
- [Did You Look? Skin Integrity Bundle](#)
- [Spina Bifida & Protecting your Skin](#)
- [Skin Integrity and Equipment Considerations](#)

The New York State Smokers' Quitline is a free service providing options to support individuals who use tobacco and/or vape products and are seeking help to quit. Specialists provide tailored coaching assistance and a supply of free nicotine replacement therapy medication (patches, gum, and/or lozenges). Nicotine medications are also available through an online application. Those reporting a disability or behavioral health condition are offered additional coaching tailored to individual needs and an extra supply of nicotine medications. Visit [HERE](#) for more information.

Spina Bifida Resource Network (SBRN) Empowerment Zone Newsletter: Check out the SBRN EZ Newsletter including articles on Scoliosis and Building Self-Empowerment [HERE](#).

Montefiore Healing Arts offers music and guided exercises for relaxation including meditation, muscle relaxation, guided imagery and more. Take care of yourself by indulging in tips and tricks on how to unwind. Click [HERE](#) to check it out.

Employment

The Job Accommodation Network (JAN) is a resource for employers and job-seekers. New this year, JAN launched a webcast series. The series includes monthly virtual trainings on practical guidance and information about navigating the accommodation

process, applying, and leveraging the Title I provisions of the ADA, and job accommodation situations and solutions. This series is at no cost to anyone who would like to attend and will be held at 2 PM EST on the second Thursday of each month. Register [HERE](#).

Section 55b/c programs promote hiring of veterans and individuals with disabilities: Section 55-b of the NYS Civil Service law authorized the commission to designate 1,200 positions to be filled by people living with disabilities. Section 55-c was authorized to designate 500 positions to be filled by wartime veterans living with disabilities. Click [HERE](#) for more information on the process and qualifications.

United Spinal's Pathways to Employment program is excited to share the following employment opportunities:

- **Leadership Education in Neurodevelopmental and other Related Disabilities (LEND) is seeking a Self Advocate Training Coordinator, Network Engineer, and a Device Manager.** To see if you qualify, visit [HERE](#). After submitting an application, you can follow up with Lesly St. Louis on the status of your application via email at lstlouis@unitedspinal.org.
- **United Spinal Pathways to Employment Program** has a job opportunity with Walmart as a Coordinator. To learn more about the position, click [HERE](#).
- **Families Together in New York State** is seeking to employ Family Policy Advisors to assist OCFS (Office of Children and Family Services) in developing policies and procedures that promote the voice of parents throughout the child welfare system. To apply, send your resume and cover letter to employment@ftnys.org. For any other questions or concerns, contact Daphne Brown-dbrown@ftnys.org.
- **The Office of New York State Assembly-member, Patricia Fahy**, is seeking an organized, detailed oriented, and dependable person to join their team. The position title is a Scheduler/Community Liaison. For more details on this position, email fahyschedule@nyassembly.gov with the subject line as "Scheduler/Community Liaison."

News to Use

New Year New Goals!

Byram Healthcare offers 10 Ways to Take Control of Your Health in the New Year. Don't get discouraged this year if you fall off track or feel in disarray. Let Byram Healthcare help you bounce back by visiting and reading what they have to say about forming better habits [HERE](#).

NCHPAD's New Year Resources

- [This New Year, Set Your Goals and Stick with Them](#)
- [Better Nutrition in the New Year: Setting Yourself up for Success](#)
- [Beginning the Year with a New Year's Resolution](#)
- [Motivation Through Goal Setting](#)
- [Make Your New Year's Exercise Resolution Stick This Year!](#)

Advocacy

Parent to Parent of NYS Special Education Information Center- The Weekend Family Empowerment Advocacy Series is BACK! This series prepares participants to better advocate within the education system for their own children and as a volunteer to assist other families. These six in depth training sessions are on an application basis which can be found [HERE](#). Applications are due no later than January 23rd, 2023. For any questions or concerns, contact Tina Beauparlant: (518) 381-4350 ext. 22 or tbeauparlant@ptopnys.org or

SBANYS Scholarships

Helen R. Mertens Educational Scholarship Fund: awards financial assistance to persons who have Spina Bifida and are pursuing higher education, technical training, certificate program, or driver's education.

SBANYS Frank Bucino, Jr. Memorial Scholarship in cooperation with Frank's family aims to award financial assistance to support individuals who have Spina Bifida and their immediate family's attendance at a national or regional Spina Bifida related education event. **Email admin@sbanys.org to apply!**

Research

The Hydrocephalus Association- After two years of continuously collecting data from two main surveys, a study is now published and is accessible to the public in the Journal of Neurosurgery. With input from over 1,500 people, the Hydrocephalus Association has developed their Top 20 Community Research Priorities. Read more [HERE](#).

Empowerment

Disability EmpowHER Network- EmpowHER camp applications are now open for girls ages 13-18 living with disabilities. There are up to 10 spots available. This camp is a multi-stage empowerment, skill building, and mentoring program that brings a diverse group of girls with disabilities together as they camp in the Adirondacks, complete a year long community project, and reunite in Washington, D.C.. To learn more about applying, visit [HERE](#).

Become a Developmental Disabilities Planning Councilmember

NYS DDPC Councilmembers are appointed by the Governor. They are volunteers with developmental disabilities (DD) and family members of people with DD. In addition, representatives from State agencies and other service provider organizations are members of the Council. The DDPC creates pilot projects around all life areas. Projects focus on advocacy, systems change, integration, and inclusion in all aspects of a person's life. If you are interested in becoming a council member, click [HERE](#).

Equipment Available:

A consumer has offered to donate two boxes of prescription Renacidin available used for urological irrigation. If you are in need or could get use out of this, please contact the office and we can connect you to the source! Email: socialworkintern@sbanys.org

THANK YOU TO OUR 2022 SPONSORS!

THE **DAILY** GAZETTE

*“Best wishes to
SBANYS as you
Dare to Dream
for the consumers
that you serve!”*



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WE ARE PROUD TO SUPPORT THE SPINA BIFIDA ASSOCIATION'S DARE TO DREAM GALA!



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is very proud to support this year's

Dare To Dream with SBANYS

“ As the very proud father of an extraordinary daughter with Spina Bifida, I have watched her dare to dream. I have watched her live every day of her life with passion. I have watched her embrace the epic and enthralling adventure that is life. I have watched her soar... ”



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



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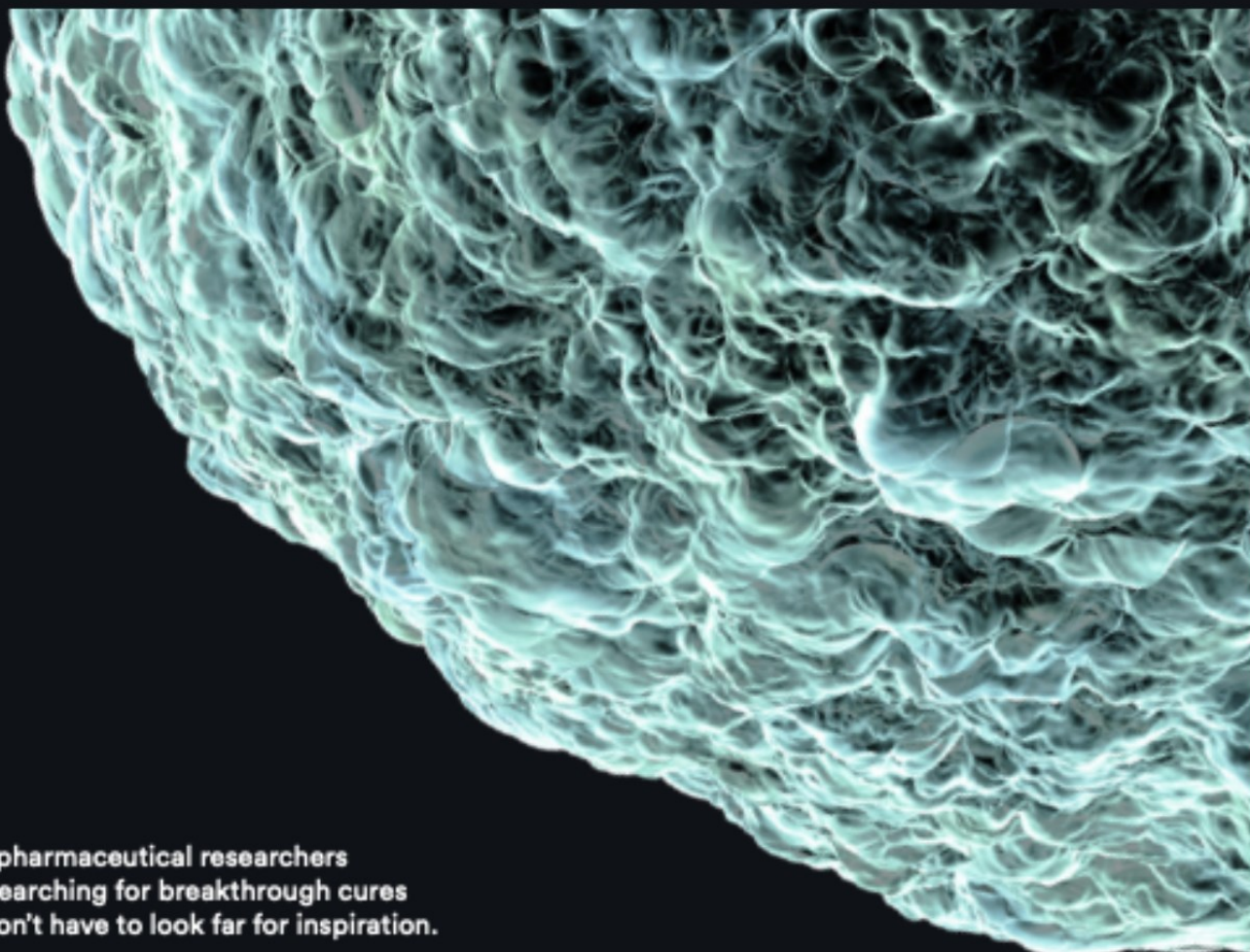
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SPINA BIFIDA ASSOCIATION
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ABOUT SBANYS

Contact: 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

Support

Health & Wellness

Awareness

Respect & Dignity

Empowerment

UPCOMING EVENTS!

Adult Group

1/24/23

Book Club: Caregivers

2/9/23

Walk-N-Roll

5/13/23 & 5/21/23



WALK-N-ROLL FOR SPINA BIFIDA

2023 Locations:

Eisenhower Park,
East Meadow, NY
Saturday, May 13, 2023

Central Park,
Schenectady, NY
Sunday, May 21, 2023

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—January 25, 2023

Dare to Dream —January 26, 2023

Governance— March 7, 2023

Board of Directors— March 11, 2023

COMMITTEES TO JOIN

Conference

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.