



Hello all!

I hope everyone enjoyed the end of summer and are now getting out to take in all the beautiful colors of fall. SBANYS has been busy celebrating Spina Bifida Awareness Month all of October, highlighting all the different advances for people living with Spina Bifida, at the same time noting the challenges. It has been a great time of education and advocacy that we will continue all year long.

Save the date! Join us on November 18th at the Hilton Garden Inn in Troy for our Dare to Dream Gala. This year we have dinner, music, a silent auction, a live auction, presentations and of course, fun! Come help us celebrate 30 years of SBANYS!

SBANYS recently launched a statewide consumer survey to help identify the lifespan and regional needs of those we serve and how we can serve the community better. The results of this survey will be included in SBANYS 2024 Operating Plan which will be produced in January. We will be recruiting new committee members, Board members, and advisors to help achieve these goals.

Looking to get involved more with SBANYS and support individuals living with Spina Bifida? We are looking for creative, enthusiastic volunteers. We have opportunities for people with all types of interests and talents looking to get involved. Please see our website or call the office for information.

Fall is in full swing and winter and the holidays will soon be upon us. I hope everyone has a safe, happy and healthy season!

Shelley Miller
Board Chair

Disclaimer: Spina Bifida Association of New York State 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 #95, OCTOBER 2023

SPINA BIFIDA AWARENESS MONTH

SBANYS PROGRAMS & NEWS

DARE TO DREAM

NEWS TO USE

SPONSORS

GET INVOLVED

SBANYS BOARD

Chair: Michelle Miller

Chair Elect: Joe Slaninka

Immediate Past Chair:

Jim Dunham

Treasurer:

Dave Wentworth

Secretary: Diane Skibinski

Directors:

Kevin Chamberlain

Chris Darby-King

Robert Derrick

Sunny Jaddu

Paul Lukasiewicz, III

Jessica Murcin

Andrew White

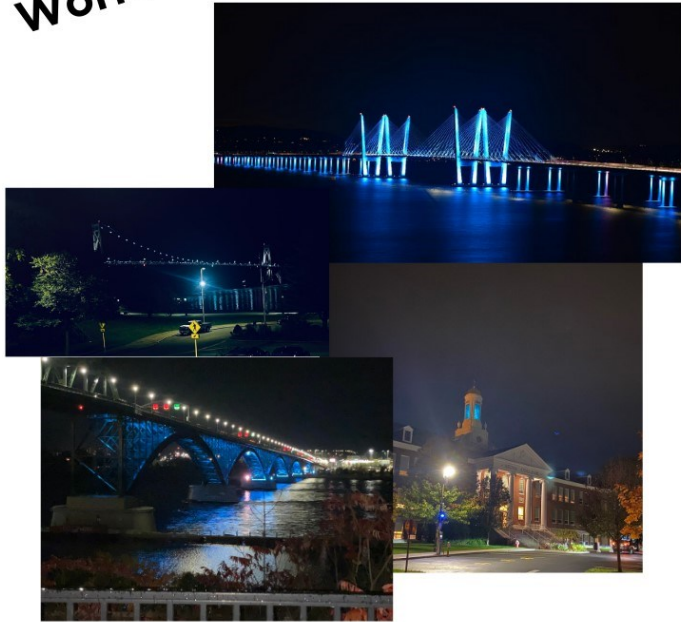
Executive Director

Julia Duff

OCTOBER IS SPINA BIFIDA AWARENESS MONTH!

See how we celebrated this year!

Light up the
World **Teal!**



Strut & Stroll
Adaptive Fashion
Show



Spina Bifida is the most common congenital birth defect that causes disability.

Spina Bifida is a birth defect, it's something you're born with.

More than half of the most common Spina Bifida brain and spine surgeries take place before a first birthday.

You cannot "outgrow" Spina Bifida, AND you can grow old with Spina Bifida.

80% of people living with Spina Bifida also have hydrocephalus.

Every year, over 1,600 babies are born with Spina Bifida in the United States.

Know the
FACTS!

Up to 68% of children with Spina Bifida develop a latex allergy.

Spina Bifida occurs in the first 28 days of pregnancy often before a woman knows she's pregnant.

There is no cure for Spina Bifida.

The severity of Spina Bifida depends where it occurs on the spine. The higher on the spine the lesion is, the greater the complications.

Spina Bifida Occulta occurs in about 10% of the adult population and most have no symptoms.

By the age of 18, almost all people with Spina Bifida will have had at least 8 surgeries.

In both Spina Bifida Occulta & Occult Spinal Dysraphism (OSD) the spine does not form properly. But only OSD affects the nervous system

The term
Spina Bifida
comes from Latin and means
"split spine"

Children and adults with Spina Bifida are at an increased risk of depression and anxiety.



Share **YOUR**
story!



SBANYS Programs & News

Advocacy

- Monday, 11/6/2023, 6:30-8:00PM, Campaign Building (email admin@sbany.org to receive the link)
- Wednesday, 11/8/2023, 7:00-8:00PM, Tools to Navigate Employment ([register HERE](#))
- Monday, 11/13/2023, 6:30-8:00PM, Meeting with Your Representative (email admin@sbany.org to receive the link)

Spina Bifida Book Club

Strangers Assume My Girlfriend is My Nurse by Shane Burcow will be discussed on Thursday, November 9th at 7:30pm via Zoom. Email admin@sbany.org to receive the link to join!

Virtual Spina Bifida Adult Group

For mutual support from the Spina Bifida community join our adult group happening on November 28th and December 26th from 5:30-7pm [via Zoom](#). Registration is required.

ADVOCACY

Add Spina Bifida to the NYS Definition of Developmental Disability

Spina Bifida as a condition is not adequately represented or served by New York State agencies, more specifically, the Office for People with Developmental Disabilities (OPWDD). This has resulted in families not receiving beneficial support services or undertaking costly legal action in order to receive these services. This further exacerbates the common challenges experienced by the community, including disjointed care, greater caregiver duties, out-of-pocket expenses, chronic illness, and excess time spent trying to access and coordinate services. **We need your help to encourage our Assemblymembers and Senators to sign on as co-sponsors of the bill that would add language about Spina Bifida to the state definition of developmental disability!**

Current Co-Sponsors:

- Assemblymember (AM) Angelo Santabarbara
- AM Scott Bendett
- AM Rebecca Seawright
- AM Monica Wallace
- AM Jen Lunsford
- AM Jo Anne Simon
- AM Amy Paulin
- AM Manny De Los Santos
- Senator Jake Ashby

TAKE ACTION NOW!





Join us as we celebrate our 30th anniversary serving the Spina Bifida community! Dare to Dream promises to be an impactful and fun-filled evening that embraces the spirit of the Spina Bifida community. Your attendance, virtual or in-person, and generous support will help us continue to build a better and brighter future for all those impacted by Spina Bifida. Dare to Dream is taking place Saturday, November 18th, from 5:00-9:00pm at the Hilton Garden Inn in Troy, NY.

HONORARY CHAIRPERSON

- Stella Porter, Reporter, WNYT Newschannel 13

EVENT FEATURES

- Live and online auction featuring over 60 exciting baskets
- New this year! Appetizers and a delicious 3-course meal
- Impactful ceremonies and recognitions
- Special musical performance by Schenectady Light Opera Company

TICKETS

- **VIRTUAL:** \$20. 6:30-8:00PM; Our virtual ticket includes access to the online and live auction, presentations and musical performances
- **INDIVIDUAL:** \$85; Individual ticket holders have access to all event features. Individuals living with Spina Bifida or their caregiver (consumer) can receive a discount by contacting the office (admin@sbany.org / 518-399-9151).
- **SUPPORTER:** \$100; Receive all the attractions of the individual ticket AND help fund a consumer in participating in the Gala! Supporter tickets are an additional \$15 to help offset the cost of consumer tickets offered at a discounted rate.
- **TABLE OF 8:** \$640; Purchase a table for 8 guests and receive a discount of \$5 off each ticket! A separate form must be completed and submitted by November 10, 2023 with the table contact name and each guest's name with meal choice.

[Purchase your ticket here!](#)

RESEARCH

The National Research Center for Parents with Disabilities

The National Research Center for Parents with Disabilities conducts research and provides training and technical assistance to improve the lives of parents with disabilities and their families. Findings are shared here on [this website](#). They also offer information sheets, research briefs, and other resources (all materials are available in Spanish as well).

MedStar Bladder Study

The Research and Rehabilitation Training Center at MedStar National Rehabilitation Hospital in Washington, DC is recruiting participants for a research study to determine the best dosage of probiotic bladder wash to reduce urinary symptoms. Participants must be at least 18 years old with neurogenic bladder; use indwelling catheterization for bladder management; and have a history of recent episodes of urinary symptoms. Washington, DC area participants may also be eligible to provide asymptomatic urine samples, with a stipend of \$20 for each sample collected. To learn more: contact Chris Riegner at (202) 877-1560 or Christopher.R.Riegner@Medstar.net

Parents of Children with Spina Bifida

Konrad Szymanski, MPH, MD and his team with the Indiana University School of Medicine built an iPhone app based on suggestions of children with Spina Bifida and their parents to help them achieve their continence goals. Dr. Szymanski needs your help to find out how user-friendly the app is and how to make it better. To be in the study, you must be a parent of a child 8-17 years old who has Spina Bifida and who experiences incontinence. Please [click on this link](#) if you are interested and to see if you are eligible to participate.

University of Alabama (UAB) Bowel Regimen Survey

Bowel continence is a top concern for adults with Spina Bifida, but researchers and healthcare providers know very little about how adults manage their bowel regimens, and even less about which medical subspecialties take ownership in managing their care. Because this information could help adults find appropriate care, researchers with the UAB are inviting adults 18+ with Spina Bifida to take a 5 to 10 minute survey. Access the survey by [clicking here](#). Please contact Principal Investigator, Carmen Tong, DO, at (205) 638-9840 or at cctong@uabmc.edu if you have questions.

Bowel Management Survey

If you are an adult with neurogenic bowel and/or bowel incontinence or a parent of a child with neurogenic bowel or bowel incontinence, [please take a moment to complete the survey](#). The survey takes about 10 minutes. The data collected will be used to encourage Medicare and other health plans to provide coverage for bowel management equipment and supplies.

SBANYS Consumer Survey

Over the next two years, our Board of Directors and staff have set a goal to successfully serve and represent individuals impacted by Spina Bifida statewide. At SBANYS, we're dedicated to making a difference in the lives of those affected by Spina Bifida. But we can't do it without you! Please provide your input and feedback to help craft our short-term and long-term goals for serving the community. Each consumer who responds to this survey by 11/1 will be entered into a raffle to receive a \$100 Gift Card! Complete the survey [HERE](#).

HEALTH

Bowel Management for Spina Bifida Support Group on Facebook: This group is for parents/guardians of children with Spina Bifida and adults with Spina Bifida to share information about bowel management. To join, search: Bowel Management for Spina Bifida in Facebook Groups.

Centers for Disease Control and Prevention's (CDC) latest initiative is aimed at improving health promotion among individuals with hearing, vision, cognitive, mobility, and self-care disabilities. The CDC has developed and rigorously tested tailored health promotion messages and materials to enhance hand hygiene, cleaning and disinfection, mask wearing, and physical distancing behaviors among this community. The primary goal of this guide is to assist both community partners and individuals with disabilities in comprehending the purpose and use of a wide range of materials specifically designed for their needs, including:

- Posters
- Flyers and Handouts
- Static Social Media Images
- Website Banner
- Magnets and Decals
- Conversation Guide
- Storybook
- Audio File

Notably, all material in this guide adheres to the accessibility standards for color contrast and assistive screen readers outlined in Section 508. Access and download Materials for People with Disabilities [HERE](#).

Lung Cancer Screening Webinar: November 28th, 2023, via Microsoft Teams at 12:00pm. The goal of this [webinar](#) is to provide education on lung cancer screening to healthcare professionals and all those interested in the topic. Webinar participants will gain tools and resources for talking with eligible clients/patients about decision-making and addressing barriers for lung cancer screening.

State Wide Public Survey to help shape New York State's (NYS) Master Plan for Aging

NYS is developing a Master Plan for Aging (MPA) that will set forth a blueprint of strategies to ensure that all New Yorkers can live fulfilling lives, in good health, with freedom, dignity, and independence, regardless of age. This survey seeks to understand the living conditions, care and service needs, and the areas of focus New Yorkers would like to see addressed in the MPA. [Click HERE](#) for the survey.

Medicare Open Enrollment runs through December 7, 2023. During this time, you can review and compare your options for health and prescription drug coverage. After checking your options, you can enroll or switch plans for the coming year. Changes will take effect on January 1, 2024. If you are satisfied with the current health care coverage and it will be available in 2024, you do not need to take any action. For more information or to compare plans, you may visit [Medicare.gov](#) or call 1-800-MEDICARE.

EMPLOYMENT

United Spinal – Pathways to Employment Work Readiness & Education Program: This program leads you through the pivotal stages required for optimizing your job hunt, such as crafting a compelling resume, preparing for interviews, navigating benefits, and leveraging technology to advance your employment success. Through the Work Readiness program, you will have the opportunity to strengthen your network and connect with individuals who have similar life experiences and professionals to partner with you during your journey! Applications are due 11/13/2023 and the program starts 1/10/2024. Click [HERE](#) for more information!

Intro to Acces-VR Webinar (Adult Career and Continuing Education Services –Vocational Rehabilitation): What it is, How to Apply and What to Expect. Taking place Thursday, November 2nd, 10:00-11:30am. Register [HERE](#).

News to Use

ADVOCACY

Election Day: November 7th!

Making sure that we vote in the national, state, and local elections is extremely important. Voting is a right that everyone has. If you are someone or know of someone who has a developmental disability and needs help voting, please talk to a care manager or a supportive staff member. Make sure to go to your local elections and cast your vote, because your vote is your voice. Visit this [poll site locator](#) to know where you can vote!

The Supplemental Security Income (SSI) program has many rules that have not been updated since 1989. In some cases, these rules prevent people from taking new jobs, getting married, and saving for emergencies. Because of these unfair rules, tens of thousands of people lose their SSI benefits every year or get their benefits significantly reduced. SSI rules must be updated to improve the lives of millions of people who rely on this critical program, including people with disabilities and their families. [TAKE ACTION:](#) Urge your members of Congress to support people with disabilities by co-sponsoring the bipartisan SSI Savings Penalty Elimination Act.

CAMPS

Double H

Double H's Adaptive Winter Sports Program, offers children ages 6-16 dealing with chronic and life-threatening illnesses the opportunity to participate in alpine skiing and snowboarding in the beautiful Adirondacks. Lessons run every weekend from January 7th through March 17th on Double H's very own ski hill. Click [HERE](#) to learn more!

EmpowHer Camp

EmpowHer Camp takes young women with disabilities on a yearlong program mentorship, developing leadership and independent living skills, and making a change in their company around emergency preparedness for people with disabilities. Learn more about EmpowHer Camp by clicking [HERE](#).

SBRN Adult Empowerment Retreat: "Live Your Best Life"

The annual Empowerment Retreat is designed to foster radical self-acceptance and community building in adults (21+) with spina bifida and other disabilities. This year's event will be hybrid. The in-person workshops and festivities will be at the Delta Hotels Woodbridge NJ from Friday to Sunday. You can choose to attend 1, 2, or all 3 days. SBRN will sponsor a luncheon on the Saturday. The retreat will also be accessible online through Zoom. Registration is required and there is a sliding scale fee. Click [HERE](#) to learn more!

HOUSING

The **TRIP & RCHR NeighborWorks®** Home Ownership Center opened in Troy in 2001, creating a one-stop shop for homebuyers and homeowners. Through the Homeownership Center, services provided include homebuyer education, financial counseling, down payment and closing cost grant assistance, matched savings programs, landlord training, home maintenance training, and more. All our services are now online at [triponline.org](#) through our Compass Portal. [Click HERE](#) to learn more.

Thank you to our Titanium Sponsor!




We're working to drive patient-centered progress in innovation, affordability and access to life saving prescription drugs.



Learn more at [PhRMA.org](https://www.Phrma.org)



Thank you to our Titanium Sponsor!



The **Albany Med Health System** is proud to provide a single, unified source for health care, scientific discovery, and medical education in our communities.

Our important partnership with the **Spina Bifida Association** ensures children and adults affected by spina bifida receive the very best coordinated multi-disciplinary care right here at home.



ALBANY MED Health System

ALBANY MEDICAL CENTER

albanymed.org



SPINA BIFIDA ASSOCIATION
OF NEW YORK STATE

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!

Advocacy Boot Camp

November 6th and 13th, 2023

Dare to Dream Gala

November 18th, 2023

Adult Group

November 28th, 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!

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.