



SPINA BIFIDA ASSOCIATION OF NEW YORK STATE



Hello Friends,

We are the Spina Bifida Association of New York State (SBANYS)! New name, but same mission. We knew that we were supporting those with Spina Bifida and their families throughout New York State and with funding from the New York State budget, we decided that our name needed to reflect our actual service area. We moved into a larger office, with a new address as a result. An Open House to celebrate our official name change and a ribbon cutting for our new office was held with some of our founders, and local and state dignitaries. It was a great success.

Recently we held our first in person Walk-N-Roll since 2019 at Central Park in Schenectady, along with events at "hotspots" in Poughkeepsie and Eisenhower Park in Long Island. We were thrilled with the participation in all locations. The fundraising was very successful, but the most important aspect is always the networking and sharing of ideas. We also held our second annual Spina Bifida Day at Citi Field. It was a beautiful day, with almost a hundred of us in teal and the Mets won! Please look throughout our newsletter for images from all of the above events.

HELP WANTED! We are hiring a new Case Manager. Please look for the details on our website (www.sbanys.org) and consider applying or share with a dynamic individual that you know would be great.

Get out your calendar! We are gathering a group to attend the August 30th Tri-City Valley Cats game. Look for information on how to participate in this letter. As you know, October is Spina Bifida Awareness Month. We will be kicking it off with a National SBA Education Day on 10/1/22, offering a 4-part Financial Planning Series and launching a new book club! It's also not too early to start planning on attending our Dare to Dream Gala taking place on November 19, 2022. Our Dare to Dream Committee has been working hard already planning and preparing for a fun event featuring unique silent and live auction items, hybrid participation opportunities, entertainment and awards ceremonies!

We could not do all that we do without you! We greatly appreciate all of your support—emotional, in person and financial. Keep in touch with what we are doing by checking our website (www.sbanys.org) and please consider joining our team by volunteering on a committee or at an event.

Thank you,

Jim Dunham, 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 #90 JULY 2022

WELCOME LETTER

WALK-N-ROLL FOR
SPINA BIFIDA

SBANYS UPDATES

WALK-N-ROLL

SPONSORS

SBANYS PROGRAMS

NEWS TO USE

DARE TO DREAM

GET INVOLVED

SBANYS BOARD

Chair: Jim Dunham

Chair Elect: Michelle Miller

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Margaret Smith

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Secretary: Jessica Ryder

Directors:

Kevin Chamberlain

Chris Darby-King

Robert Derrick

Crystal Hoey

Paul Lukasiewicz, III

Diane Skibinski

Joe Slaninka

Andrew White

Executive Director

Julia Duff

Walk-N-Roll for Spina Bifida, 5/14/22

Thank you to our Walk-N-Roll Committee!

Co-Chairs: Heather Horwedel and Shelley Miller and members: Pauline Cassillo, Paul Lukaszewicz, Jerry Malloy, Joe Slaninka, Peggy Smith, and Jessica Ryder. **Email admin@sbany.org to join the fun in 2023!**



Thank you to our Hot Spot Ambassadors: Joe Slaninka, SBANYS Board Member and Dr. Rachana Tyagi, Associate Director of Neurosurgery at WMC Health.



Thank you to our Sponsors: Byram Healthcare, The Daily Gazette, Rivers Casino, Mobility Works, Coloplast, Numotion Foundation, Rotary Club of Scotia, DeCrescente Distributors, Stewart's Shops, Manhattan Bagel, Celsius, Pepsi, Bussani Mobility, Westchester Medical Center, Cardboard Memories Sports Memorabilia, Dunkin', Mineola Bike Shops, and Rotary Club of Williston Park.



Thank you to our Nonprofit Vendors: Capital District Center for Independence, Double H Ranch, Ms. Wheelchair New York, National Alliance on Mental Illness, NYSARC Trust Services, NYS Justice Center, and Parent to Parent

Thank you to our SBANYS Team: Board of Directors, Case Manager, Social Work Interns, SBANYS Interns and Volunteers

Thank you to our Partners: Photographers Lance Moore and Jody Dobson, DJ Lou Roberts, The Chapters Rap with Steve Vaccaro and Bob Damato, AYCO and Wayne Wizzo.

Congratulations to our contest winners!

Top Team: Long Island Bifs

Top Individual: Edward Constantine

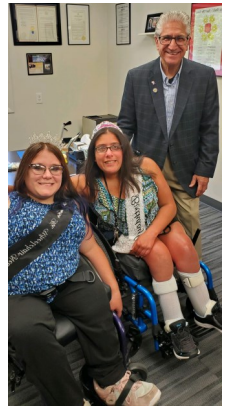
Team Spirit: Miracle Marley



SBANYS Updates

Spina Bifida Association Clinical Care Meeting (CCM): SBANYS' recently attended the National SBA CCM at Boston Children's Hospital. The CCM is an opportunity for healthcare professionals serving the Spina Bifida community to network, partner, and collaborate. **The CCM also included the launch of the Lifespan Bowel Management Protocol.** Check out the protocol and presentations [HERE](#).

Open House: SBANYS celebrated a new office, name, and official territory on Saturday, June 25th with a celebratory ribbon cutting, wine tasting, raffle, give aways and office tour!



Spina Bifida Day at Citi Field: SBANYS headed to Citi Field for a day at the ballpark and was recognized by the NY Mets with the Team Spirit Award!



Sepsis Webinar: The National Spina Bifida Association recently hosted a webinar on Sepsis - which is one of leading causes of death for people with Spina Bifida. Learn the signs and symptoms of sepsis and what you can do to prevent it by watching the webinar: [HERE](#)

We are hiring! SBANYS is seeking to hire a Case Manager for up to 40 hours each week. The position includes individual and family services, education outreach, clinical care, and programming for those in the Spina Bifida community. Please find the full job posting, description and application [HERE](#).

2021 Annual Report: [Our 2021 Annual Report is now available](#) with details on our 2021 program and service highlights, consumer reach and impact, financials, volunteers, and how to get involved.

SBA Chapter Award: SBANYS and SBA of Greater New England were awarded this year's SBA Chapter Award for Innovative Programming for the conceptualization and execution of the Strut & Stroll, Fashion Show For All! Watch this year's Strut & Stroll [HERE](#).

Thank you to our Walk-N-Roll Sponsors!



Mobility Works in Albany is now certified to quote and install home and business access equipment and parts such as outside ramps, vertical wheelchair/scooter lifts, straight and curved stairlifts, as well as, overhead ceiling track & harness systems.

From the initial free home assessment to determine the right solution for you, to guaranteed installation by their factory trained installers, Mobility Works ensures your accessibility solution is customized to your specific needs.

For more information, visit:

<https://home.mobilityworks.com/>



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call 800-364-6057**



**Rivers Casino staff at the
2022 Walk-N-Roll for Spina Bifida!**

Programs

Spina Bifida Provider Survey: This winter, we developed a survey requesting information from our consumers about the generalist and specialty providers they see in order to better respond to requests from our community about finding experts in the field. **SBANYS responded to over 50 requests for a provider referral last year—that is near once a week!** With your feedback, we can better respond to consumers statewide looking for providers who have treated a person living with Spina Bifida. We also intend to identify areas where expertise is needed, and share Healthcare Guidelines with regional hospitals and offices. Survey respondents who participate by September 1st, and complete the survey in full, will be entered into a raffle to win a \$50 gift card. Help us build our provider database by completing the survey [HERE](#)!

Equipment Exchange: Two 24 x 1-3/8 brand new wheelchair tires are available to the community! They have never been used, available for free, and are latex-free. Contact admin@sbanys.org if you are interested!



Adult Group: Join our adult group at one or more of the meetings taking place at 5:30pm EST throughout the rest of 2022: 8/23, 9/27, 10/25 (World Spina Bifida Day!), 11/22, 12/27. Register to attend [HERE](#).



Tri-City Valley Cats: Tuesday, 8/30 at 6:30pm come cheer on the Tri-City Valley Cats (80 Vandenburg Avenue, Troy, NY 12180) as they take on the Sussex County Miners. SBANYS has blocked seats for guests to sit together when you purchase tickets through the portal. Tickets are \$11.00 each **AND** \$2.00 from every ticket sold is donated to back SBANYS! [HERE](#) is the link to the portal which requires using passcode 30sbanys (not case sensitive). If you have questions about the venue, click [HERE](#).

Adult Leadership Academy: Individuals living with Spina Bifida ages 18+ are invited to join SBANYS and Life Coach Rita Hudgens for a free 12-week course via Zoom. By completing the program, attendees will have the knowledge and tools to rise up as leaders within the group or workplace, increase independence, establish a support system, and know how to be proactive in taking responsibility for their commitments. If you are interested in participating, please complete this [SURVEY](#). SBANYS will follow up with more details.

SPINA BIFIDA AWARENESS MONTH IS 2 MONTHS AWAY!

Here is what we have lined up so far...

National SBA Education Day for Adults: Saturday, 10/1/2022, via Zoom, 12:00pm-5:30pm

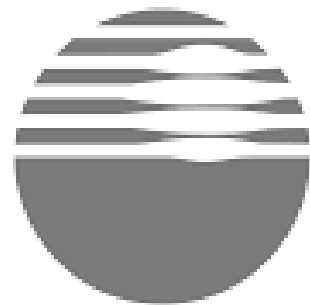
Topics include: Self-Advocacy, Bowel Management, Men and Women's Health, Understanding Executive Functioning, Initiating a Wellness Plan that works for you, and wrap up with a happy hour toast and networking event. Save the date! Registration will be available soon!

Financial Planning Series: 10/6, 10/12, 10/20, and 10/27 at 6:00pm EST via Zoom

October is also Financial Planning Month and SBANYS is partnering with the Association of Financial Educators to provide a 4-Part Webinar Series on topics including [budgeting basics](#), [financial planning](#), [wills, trusts and power of attorneys](#), and [SSI/SSDI](#). Click the event topic to register!

Book Club: This October SBANYS and chapters across the country will be launching two separate book clubs for adults living with Spina Bifida and parents/caregivers of individuals with Spina Bifida. The book club is intended to meet quarterly and facilitate meaningful conversations amongst peers. Stay tuned!

Thank you to our Walk-N-Roll Sponsors!



News to Use

SBANYS Scholarships

- **Helen R. Mertens:** For individuals who have Spina Bifida and are pursuing higher education, technical training, certificate program, or driver's education
- **Frank Bucino Jr. Memorial:** For individuals who have Spina Bifida and their immediate family's attendance at a national or regional Spina Bifida related education event.

Email admin@sbany.org to learn more and apply in 2022!

National Spina Bifida Association (SBA) Research Updates

- SBA recently co-authored an article titled **Establishing the First Community-Centered Spina Bifida Research Agenda**. Elsevier has provided our association with 50 days' free access to the article which can be found [HERE](#).
- **All of Us Research Program:** SBA recently hosted Karl Cooper from the All of Us research program which aims to collect health data from over a million people, including those who have not been well represented in the past. Researchers will use the data to study many different conditions, including cancer, diabetes, depression, asthma, and other diseases. When scientists understand what makes us all unique, they can work on uncovering patterns and design more personalized care. The research could also lead to future medical breakthroughs. Learn more about the program and how you can participate [HERE](#).

DDPC Art Contest

DDPC is looking for art submissions from self-advocates in the I/DD community that explains your experience during the pandemic. The winning artist will have their artwork featured on the cover page of a report on the impact of the NYS response to COVID-19 that will be sent to the State Legislature. All submissions should be sent to anna.derosa@ddpc.ny.gov by August 15th.

Spina Bifida and Hydrocephalus Conference

- From 9/5-9/9, the International Federation for Spina Bifida and Hydrocephalus is hosting a conference with discussions and presentations from various disciplines on recent innovations, concerns, challenges and solutions with the goal of improving the quality of life of people with Spina Bifida and their families. You can find the agenda and registration link [HERE](#).

July: Disability Pride Month and the Americans with Disabilities Act (ADA) Anniversary

- July 26th 2022 marked the 32nd anniversary of the passing of the ADA. Since the passing of this integral legislation, members and friends of the disability community have celebrated July as Disability Pride Month. Learn more about [Disability Pride](#) and the ADA [HERE](#).

Double H Ranch

- Double H is hosting their first ever camp Prom—an event for all previous campers aged 21 years and older. The event is 9/24 from 1:30pm-8:00pm at Double H Ranch. For more information, click [HERE](#).
- Save the date! The Spina Bifida Fall Family Weekend is taking place 10/21-10/23 at Double H Ranch! Individuals living with Spina Bifida between 5-21 years of age and their family members are invited for a weekend of fun in Lake Luzerne to enjoy activities such as an indoor pool, a high ropes course, archery, picnic pavilion, stage area, arts & crafts and more. Double H Ranch does not charge any of the participating families.
- Thistle Be Perfect Too—our plaza neighbor is helping make scarves and lap blankets for our Double H campers this year! Be sure to visit them at 123 Saratoga Road, Scotia, NY to knit/crochet something special for our group!

Dare to Dream with SBANYS

Save the date for our 10th Annual Dare to Dream Gala!

Live Event & Online Auction

Saturday, November 19, 2022 * Wolferts Roost Country Club

Honorary Chair: Edward V. Wilcenski, Esq.

You Make a Difference Award: The School of Social Welfare, SUNY Albany

Individual & Corporate Sponsorship Levels

\$5,000 Titanium Sponsor

- Acknowledgement on stage the night of the event. Opportunity to speak.
- Full-page color ad, on inside or back cover of event program and in one SBANENY newsletter
- Logo & listing, with a link to your website, on SBANENY website & 4 Facebook posts
- Acknowledgement in event press releases
- Logo placed on 10 slides during the event presentation
- Reserved table for ten guests (or ten tickets)
- 1 hour webinar on your services hosted by SBANYS
- \$50 Facebook advertisement

\$2,500 Gold Sponsor

- Acknowledgement on stage the night of the event. Opportunity to speak.
- Full-page ad in event program and in one SBANENY newsletter
- Logo and listing, with a link to your website, on SBANENY website & 3 Facebook posts
- Logo placed on 5 slides during the event presentation
- Reserved table for ten guests (or ten tickets)
- 30 minute webinar hosted on your services hosted by SBANYS

\$1,000 Silver Sponsor

- Acknowledgement on stage the night of the event
- Half-page ad in event program & in one SBANENY newsletter
- Logo listed on SBANENY website & 2 Facebook posts
- Logo placed on 3 slides during the event presentation
- Four (4) tickets to the event

\$500 Bronze Sponsor

- Acknowledgement on stage the night of the event
- Quarter-page ad in event program and name listed in one SBANENY newsletter
- Name listed on SBANENY website & 1 Facebook post
- Logo placed on 1 slide during the event presentation
- Two (2) tickets to the event

Honorary Committee

\$275 Two Star Honorary Committee

Two complimentary event tickets

Listing on website and event materials

\$150 Shining Star Honorary Committee

One complimentary event ticket

Listing on website and event materials

Event Program Advertisements:

\$400 Full page - \$250 Half page -

\$100 Quarter page



SPINA BIFIDA ASSOCIATION
OF NEW YORK STATE

ABOUT SBANYS

Contact: admin@sbanys.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

August 23, 2022

Tri-City Valley Cats Game

August 30, 2022

Leadership Empowerment Series

August/September, 2022—Official date TBD



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

Dare to Dream—August 17, 2022

Development—August 24, 2022

Governance— September 6, 2022

Board of Directors— September 10, 2022

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.