



SBANENY Newsletter

WELCOME LETTER

Happy 2022!

As we begin this new year, we automatically look back to 2021. I am amazed and thrilled by all of the events and programs that we were able to accomplish, with your generous help and support in 2021. The Spina Bifida Association of Northeastern New York (SBANENY) was able to meet all of the challenges presented via in person, virtual and hybrid strategies. I could not be prouder with how we all pulled together and provided the support that we did in 2021 for individuals and families with Spina Bifida. Great teamwork everyone!

This month's focus is on Advocacy. As you receive this letter SBANENY staff and volunteers are meeting with local representatives to talk about our mission, goals, and needs for the upcoming year. We have previously been able to establish positive relationships with our representatives. In addition, we are following up with our representatives for their support and encouragement during the past year. You can click [HERE](#) to find out more.

I am pleased to announce that we will again be collaborating with the Spina Bifida Association on Greater New England (SBAGNE) to present our 2nd virtual adaptive fashion show, the "Strut and Stroll." Creative designers from across the country will be providing clothing specifically adapted to meet the needs of those with Spina Bifida, which will be modeled by many from our local Spina Bifida chapters. I found last year's show fascinating and inspiring. A video production of the show will be presented live on March 17th! We will also be joining multiple SBA chapters throughout the country in hosting Watch Parties for the upcoming Winter Paralympic Games. Stay tuned and please join us.

From April 2nd to May 14th, we will be offering a 100-mile challenge! Like last year's 30-day fitness challenge, we will be offering prizes to participants who complete health/wellness activities during the challenge. This will be a great way for all of us to get ready for the spring and the 2022 Walk-N-Roll for Spina Bifida. Planning has already started for our May 14th Walk N Roll. Our Walk N Roll committee is focused on having our event in person at Central Park in Schenectady. With good luck, we will see everyone there.

Please continue to stay involved and informed by routinely visiting our website at sbaneny.org to hear about news and updates. Thank you very much for your ongoing support and involvement. We couldn't do it without YOU.

Jim Dunham
Board Chair

Disclaimer: Spina Bifida Association of Northeastern New York 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 #88
JANUARY 2022

WELCOME LETTER

DARE TO DREAM WITH
SBANENY

BYRAM

ADVOCACY

SURVEY RESULTS

SBANENY PROGRAMS &
EVENTS

NEWS TO USE

GET INVOLVED

SBANENY BOARD

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Dare to Dream

125 virtual
and live
attendees

\$39,000
raised for
SBANENY

105
baskets
won

[Watch the evening presentation here!](#)

Congratulations to our Dare to Dream awardees!

- The Daily Gazette, You Make a Difference Award
- Mary-Kate Sherlock, SBANENY Volunteer of the Year
- Dr. Dennis McKenna MD, Albany Med CEO & President, 2021 Honorary Chair

FEATURED PERFORMERS

Jennie Angel,
Official Member of
The Academy of
Country Music



Thank you to the 2021 Dare to Dream Planning Committee!

- Abby Mundell
- Ann Humiston
- Carla Perrone
- Crystal Hoey
- Jessica Ryder
- Judy Fillmore
- Kevin Chamberlain
- Karen Wentworth
- Michelle Miller
- Peggy Smith
- Valerie Joseph



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Advocacy

New York State Advocacy with SBANENY

When:

- * Monday 1/24 & Tuesday 1/25— morning and afternoon meetings between 9:00am and 4:00pm

Where:

- * Meetings take place via Zoom
- * You can contact your representative via email by visiting our [ONE CLICK](#) campaign

Who:

- * Assembly: John T McDonald III, Phil Steck (completed), Mary Beth Walsh, Carrie Woerner (completed), Brian D. Miller, Angelo Santabarbara (completed), Matthew Simpson, Jeff Gallahan, Jake Ashby, Chris Tague, Patricia Fahy, Robert Smullen, Didi Barrett, Billy Jones, Richard Gottfried, Aileen Gunther, Thomas Abinanti, Helene Weinstein, Crystal Peoples, Carl Heastie, and Harvey Epstein
 - * Find your Assemblymember [HERE](#).
- * Senate: Daphne Jordan, James Tedisco, Neil D. Breslin, Mike Martucci, Michelle Hinchey, Daniel G Stec, Pamela Hemling, Peter Oberacker, Samra Brouk, Gustavo Rivera, Liz Krueger, Andrea Stewart-Cousins, and Patrick Leahy
 - * Find your Senator [HERE](#).



What: This year 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, SBANENY, and fellow advocates across the country

When: February 27th—March 1st

Where: Virtual, via Zoom

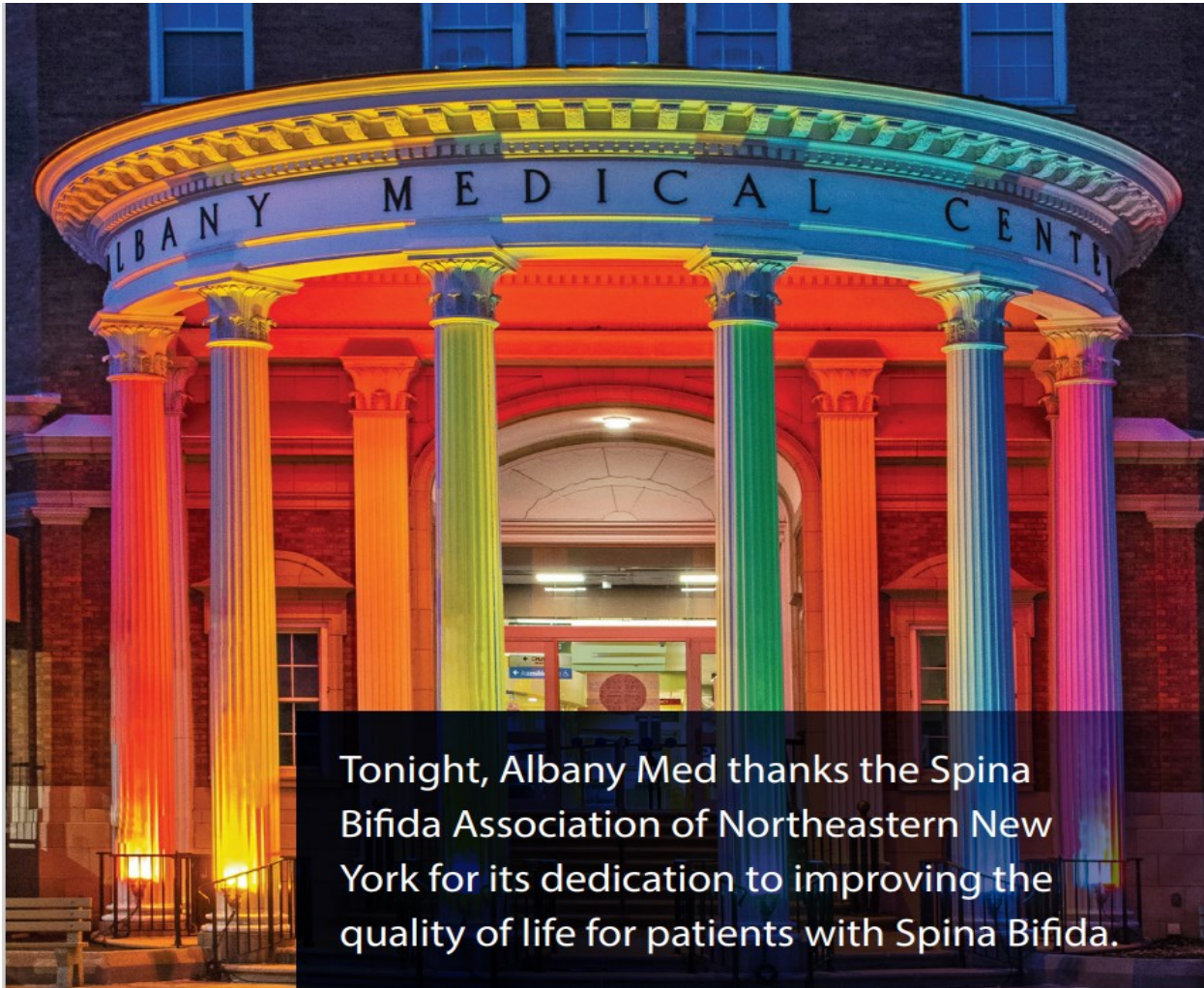
Who: Consumers who want to advocate with federal representatives in New York State

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 SBANENY!**

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

Dare to Dream Titanium Sponsor



Tonight, Albany Med thanks the Spina Bifida Association of Northeastern New York for its dedication to improving the quality of life for patients with Spina Bifida.

We are proud to serve as the only comprehensive transitional care clinic for pediatric and adult Spina Bifida patients in our region. We applaud our leadership, including President and CEO **Dr. Dennis P. McKenna**, for their support of our efforts to provide lifelong, compassionate care for Spina Bifida patients.

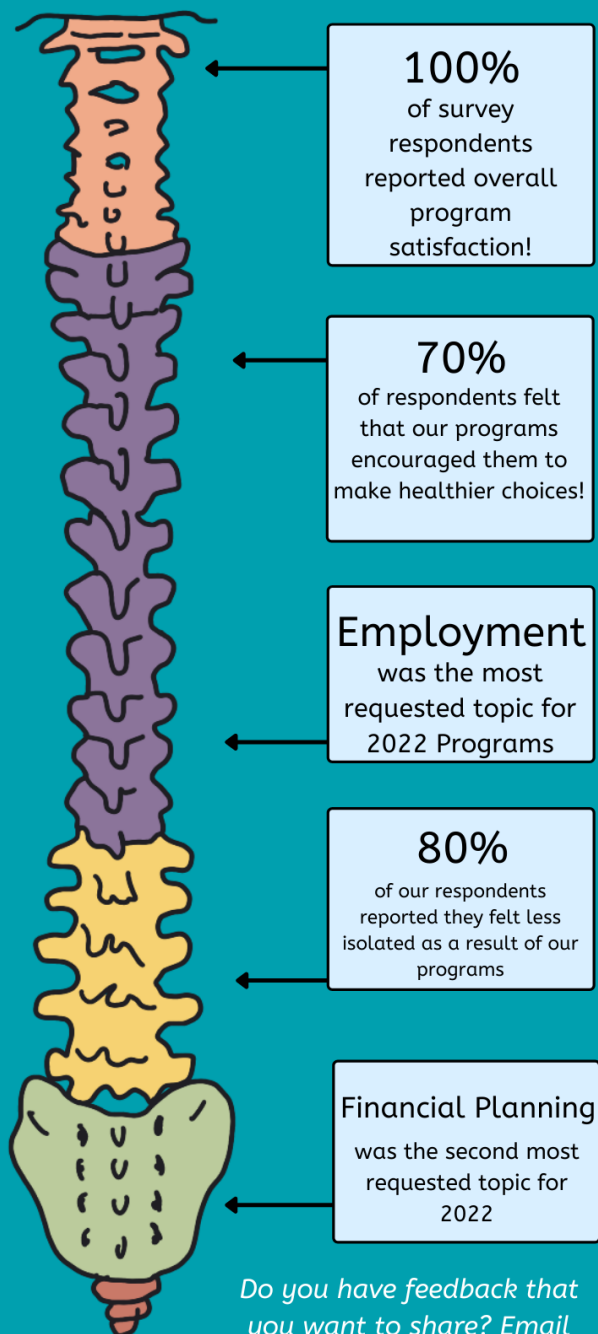
SBANENY Survey Results

Our 2021 End of Year Survey results are in!

SBANENY's mission is to bring you the best services possible, which is why we value your feedback and comments. In 2021 we shared two surveys asking our consumers what they wanted to see in 2022. See below for an update and what to expect in 2022.

FEEDBACK BREAKDOWN

SBANENY Shared two surveys to over 200 consumers across New York State!



Why does feedback matter?

Your feedback is important for many reasons:

1. Our programs and services are person-centered, meaning they are designed to fit the most immediate and pressing needs of our community. Sharing your needs and wants for 2022 helps us plan effectively.
2. We use it to grow! Each year we meet new individuals and families impacted by Spina Bifida. Your feedback allows us to advocate the importance of SBANENY programs and secure funding to support our growing consumer base.
3. Nothing about you without you! We strive to include consumers on our Board of Directors and planning committees, but this is not a comprehensive reflection of the various statewide needs. Your voice helps make an impact in your personal life and consumer's lives across NYS.

What Can We Expect to See in 2022?

1. Virtual program opportunities! Virtual programs will continue to be offered to all consumers and families statewide.
2. More in person events! SBANENY is tentatively planning in person events, including our 2022 Walk-N-Roll. SBANENY is committed to keeping our consumers safe by including COVID-19 safety measures.
3. More partnerships with local agencies and healthcare providers, including Albany Medical Center, Financial Planners, Employment Services, and Health & Recreation facilities.
4. Collaboration with other SBA chapters in different regions of the USA to provide programs and connect SBANENY consumers with peers far and wide!
5. The release of SBANENY's 1st Resource Guide: created by SBANENY staff the resource guide is a collection of NYS resources for Housing, Healthcare, Employment, Systems Navigation, Benefits, and more.
6. The distribution of the SBANENY program archive, a collection of recordings of past webinars and events for you and your family to enjoy from the comfort of your own home!

[You can still complete a survey to share your input on our 2022 programs and services.](#) We look forward to hearing from you!

Dare to Dream Titanium Sponsor

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SBANENY Events & Programs

January 25th, 5:30PM, Virtual Adult Group: Crip Camp Watch Party

Our Adult Group will be meeting on the 25th at 5:30 for a virtual Crip Camp watch party. A discussion about themes in the film such as: sexuality, the disability rights movement, and stigma will follow the viewing. Click [HERE](#) to register.

January 27th, 7:00PM, People with Hydrocephalus and Spina Bifida: COVID Conversations

Join SBANENY and the Hydrocephalus Association and featured speakers Dr. Abbott and Dr. Siasoco to discuss what is new, including vaccine updates. FAQ to follow. ASL interpretation provided.

- **Registration Link:** <https://tinyurl.com/Jan27Reg>
- **Registration Phone Number:** 718-839-7278

February 2022, Rivers Casino Charity of Choice

Throughout the month of February, guests of Rivers Casino will be able to donate vouchers, money, and chips with monetary value through the donation boxes located on the casino floor. In addition, guests will be able to select SBANENY to receive remaining monetary amounts on their vouchers when utilizing the Ticket Redemption Machines (TRM).

March 2022, Paralympic Watch Parties

Spina Bifida chapters and communities from across the country are excited to come together and celebrate the Paralympic Games! Join us in watching the Winter Paralympics and highlighting the athletes living with Spina Bifida!

March, 17 2022, 2nd Annual Strut & Stroll: Fashion For All

The Spina Bifida Association of Northeastern New York and Spina Bifida Association of Greater New England are hosting our 2nd virtual Strut & Stroll: Fashion Show For All. Models with Spina Bifida ages 4+ will be wearing brands/designs from: Zappos, Be Free, Charlotte Letter, Friendly Shoes, Stride Rite, IZ Adaptive, Redefining Spina Bifida, Punkin Futz, and Koolway Sports. Following the premier of the show, designers will participate in a roundtable discussion facilitated by Kaycee Marshall.








April 2nd-May 14th, 2022, 100 Mile Challenge

Join SBANENY and SBA's of Greater New England, North Texas, Iowa, & Arizona as we put a spin on our Wellness Challenge this year! Kicking off on Saturday April 2nd with a Virtual Education Day, over the course of 6 weeks, consumers will be connected to peers and resources to promote healthy living. Miles can be accumulated through various aspects of health (sleep, hydration, exercise) and there will be prizes for participation and completion.

May 14th, 2022, Walk-N-Roll for Spina Bifida


WE ARE BACK in person for the 2022 Walk-N-Roll for Spina Bifida. The event is taking place in Central Park in Schenectady, NY and at a second location for our NYC families at Eisenhower Park. The event will include raffles, contests and prizes, and sponsor and vendor opportunities. Check out our sponsor opportunities [HERE](#). Save the date! Registration will go live 2/14/2022.

For more information on SBANENY's program and events calendar, contact Conlee at casemanager@sbanenyn.org. You can keep an eye out for an email invite from Conlee with registration links in the coming weeks! Make sure we have your most accurate method of contact so you can stay informed.



People with Hydrocephalus and Spina Bifida: COVID Conversations

THURSDAY, JANUARY 27 @ 7:00 PM



Ira R. Abbott, MD
Director of Surgical Neuro-Oncology at Children's Hospital at Montefiore (CHAM)
• Specialty: Epilepsy, Hydrocephalus, & Moyamoya



Vincent Siasoco, MD
Director of Primary Care & Family Physician at BEK CERC
• Specialty: Care of people with DD



Dare to Dream Sponsors

Vanessa & Kevin Chamberlain



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NEWS TO USE

COVID-19

Excelsior Pass Plus: How to Get Proof of Your Vaccine on your Phone!

- If you do not wish to carry your COVID-19 vaccine card, you can download the NYS Excelsior Pass in the app store, which will display your status. Click [HERE](#) to read more!

COVID-19 Booster Shot Information

- The CDC is recommending a booster shot for individuals who are over 6 months out from their most recent vaccine dose. Speak to your healthcare provider to determine if the vaccine is right for you. Click [HERE](#) to find vaccine locations.

Free At Home COVID-19 Tests

- Every home in the U.S. is eligible to order **free** at home COVID-19 tests. Orders will usually ship in 7-12 days. Click [HERE](#) to learn more and sign up to receive yours.

EMPLOYMENT

Schenectady County Connects: Job Trainings

- Schenectady County Connect is offering virtual workshops on resume development, employment skills, services, career fairs, and more! Check out the January classes [HERE](#) and keep an eye out for the February Calendar coming soon!

SBA SURVEY

Vaccine Survey for the Spina Bifida Community

- This survey is sponsored by the SBA, and the Association of University Centers on Disabilities (AUCD), in conjunction with Duke University. It focuses on health and wellness issues that may affect adults and children with Spina Bifida. Results will help us understand how the Spina Bifida community views the COVID-19 vaccine. Click [HERE](#) to participate.

HEALTH & WELLNESS

National Center on Health, Physical Activity and Disability (NCHPAD): Inclusive Home Workout Kit

- NCHPAD has a free home workout kit, containing videos that demo safe and fun exercises you can do at home! Click [HERE](#) to download your free copy.

Special Olympics: Super Star Training Videos

- Special Olympics is releasing weekly videos with home based stretches and exercises! Start at Super Star level and work your way up to Master from the comfort of your own home. Click [HERE](#) to get started.

The ARC Virtual Program Library

- Access past programs from the comfort of your own home! The ARC has now launched its virtual program library containing a collection of free and paid virtual experiences. Click [HERE](#) to learn more and start exploring!

2022 SBA Virtual Adapted Fitness Club

- Whether you're looking to connect with friends from across the country or are looking to kick off the new year with a fitness routine, there is something for everyone. Join SBA at 11am each Saturday and at 7pm each Wednesday for rotating adapted fitness session, from chair yoga to adapted Zumba. The program is sure to offer some of your favorite ways to move and new ideas, too. Monthly wellness webinars will also be added to our calendar. Click [HERE](#) to learn more.



SCHOLARSHIPS

The ARC: Scholarship Opportunities

- Are you a college student pursuing a degree in Human Services, Special Education, Social Work, or Law? The ARC provides scholarships for college students in these areas. Click [HERE](#) to learn more about the 2022 scholarship application cycle.

SBANENY Scholarship Opportunities

- Did you know SBANENY offers three scholarships to support individuals with Spina Bifida?
 - **Helen R. Mertens:** Scholarships for individuals with Spina Bifida pursuing higher education, technical training, or drivers education.
 - **Frank Bucino Jr. Memorial:** Scholarships supporting individuals with Spina Bifida attending a national or regional Spina Bifida Conference OR in the pursuit of education or technical training.
 - **Technology and Related Supports:** The purpose of this scholarship is to provide financial assistance to individuals and families living with Spina Bifida to provide or improve access to virtual opportunities as a result of the COVID-19 pandemic.
- Click [HERE](#) to learn more and apply in 2022!

NEWS TO USE & WAYS TO GET INVOLVED

Office for People with Developmental Disabilities (OPWDD)

Early Intervention Coordinating Council: Parent Recruitment

- The NYS Early Intervention Program (EIP) is looking for 2 parents to join the Coordinating Council. Parents will need to have a child who is 6 or younger with a developmental disability. The Council seeks to improve EIP for all families and add a diverse perspective. Email BEI.SSIP@health.ny.gov if you are interested.

Navigating OPWDD Self Direction Program: Webinar

- The Southern Tier Special Ed Task Force is hosting a webinar all about OPWDD Self-Direction program. Ask questions to help you better understand if self-direction is the right choice for you. Hear a parent perspective on the process and hear about the services available and how they can meet the needs of your loved one. **This event is taking place on January 26th at 6pm.** Click [HERE](#) to learn more.

OPWDD Announces Expanded Crisis Services

- OPWDD has recently announced an expansion of its mobile crisis services to areas in Central NY and the Southern Tier. Crisis Services for Individuals with Intellectual and Developmental Disabilities (CSIDD) offers crisis prevention and response services to people who have both developmental disabilities and complex behavioral needs, as well as to their families and those who provide supports. The goal of CSIDD is to build relationships and supports across service systems to help people remain in their homes and communities and enhance the ability of the community to support them. Click [HERE](#) to read more.

Giving back to the Spina Bifida Community through Volunteerism

Join a SBANENY Committee!

SBANENY's event planning committees play an important role in being able to provide programs and services to the Spina Bifida community. The committees actively seeking new members are:

Direct Mail Campaign: Participate in the research, content development, and outreach plan for SBANENY's annual direct appeal. Meetings are as needed.

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 SBANENY to support programs and services. Meetings are every other month via Zoom for 1 hour.

Advocacy: Participate in meetings with representatives, identifying agenda priorities and following up with your representative.

Become a SBANENY Volunteer!

SBANENY's office relies on the support of in-person and remote volunteers to provide programs and services. There are a variety of research opportunities, administrative tasks, and project supports you can provide at the office or remotely. If you are interested in becoming an office volunteer, email admin@sbaneny.org for more information.



SBANENY's 2021 Volunteer of the Year, Mary Kate Sherlock being recognized at the 2021 Dare to Dream Gala.

Dare to Dream Titanium Sponsor

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to SBANENY as you
Dare to Dream
for the consumers
that you serve!”*



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SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK

ABOUT SBANENY

***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

January 25, 2022

Strut and Stroll Fashion Show

March 17, 2022

100 Mile Challenge

April 2, 2022



JOIN THE TEAM!

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

COMMITTEE MEETINGS

Governance—January 26, 2022

Development—January 27, 2022

Dare to Dream— February 9, 2022

Walk-N-Roll— February 15, 2022

Board of Directors— March 12, 2022

COMMITTEES TO JOIN

Conference

Walk-N-Roll

Dare to Dream

Direct Mail Campaign

Development

ESTATE PLANNING MEMORIALS & HONORARIUMS

Have you considered including SBANENY in your estate plans?

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