



SBANENY Newsletter

WELCOME LETTER

Fall Greetings,

As we approach the Holiday Season, with most of the year behind us, I wanted to bring you up to date. The Spina Bifida Association of Northeastern New York (SBANENY) has been active and vibrant. This is all due to the support that you give.

In August the New York Mets recognized SBANENY's efforts with the Team Spirit Award at a celebration on Citi Field. Many Board members and volunteers on hand had a chance to represent all of SBANENY on the field in receiving the award. Board member Joe Slaninka threw out the First Pitch, which I believe was a two fingered fastball. A SBANENY Public Service video was shown to all in attendance. It was a great time and honor.

October has been Spina Bifida Awareness Month. Hopefully you've received our periodic emails highlighting our programing, community education, social media campaigns and fundraising. It's SO important that we broaden awareness about Spina Bifida and spread the word about the things that we do to support those affected.

We had a design contest recently and the results are available online. Please check out the newly Designed To Be Loved Merchandise available at <https://willpromo.com/sbaneny/shop/home>. Each purchase supports the work that SBANENY does. You can help promote our efforts through your purchase of the merchandise. We'd also love your feedback.

Coming up on November 20th is our annual Dare to Dream event. This year we are providing a hybrid gala where you can participate online, or in person at Wolferts Roost, provided that you are vaccinated or test negative at least 72 hours in advance of the event. You can purchase tickets or check out Silent Auction goodies at <http://sbaneny.org/non-displayed-pages/archived-pages/dare-to-dream/d2d2020-2/>. This is one of our major fundraising events of the year, but also a celebration of our community and their support. The Honorary Chair is Dr. Dennis P. McKenna, CEO and President of Albany Med and our You Make a Difference Award recipient is The Daily Gazette.

Jim Alescio, Board member and past Treasurer will be stepping down from the Board, as required by our Bylaws at the end of the year. Jim has provided unselfish support and involvement to SBANENY over his six year tenure and has agreed to continue being involved on various committees. I called Jim recently to thank him for his contributions and work. We both agreed that time spent being involved with SBANENY is very rewarding, primarily due to the fantastic caring people involved.

I'd like you thank you for your current level of involvement and support. I'd also like to invite you to join us in additional ways, be they committee work, Board involvement, or in other ways of volunteering.

Thank 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 #87
OCTOBER 2021

WELCOME LETTER

SBANENY AWARENESS
MONTH

SBANENY PROGRAM
UPDATES

DARE TO DREAM

WAYS TO GIVE

NEWS TO USE

WAYS TO GET
INVOLVED

SBANENY BOARD

Chair: Jim Dunham

Vice Chair: Michelle Miller

Immediate Past Chair:

Margaret Smith

Treasurer: Dave Wentworth

Secretary: Jessica Ryder

Directors:

Chris Darby-King

Robert Derrick

Valerie Joseph

Paul Lukasiewicz

Jessica Ryder

Joe Slaninka

Andrew White

Executive Director

Julia Duff

2021 Awareness Month

Abilities Expo

Our chapter kicked off Awareness Month in a big way! This October, SBANENY was delighted to attend the Abilities Expo in New Jersey.

Featured annually in eight North American cities, the *Expos* are free, 3-day, all-access passports to the latest products, technology, informative resources, and organizations for individuals with disabilities! To learn about the other organizations and businesses present, click [HERE](#)!



St. Rose Presentation

SBANENY presented to St. Rose seniors in Natural Sciences on 10/13/2021

SBANENY and interns living with Spina Bifida presented on Spina Bifida and what we know about the cause, folic acid and prevention, impact of Spina Bifida, treatments and services for those living with Spina Bifida, societal barriers to inclusion, and provided a wheelchair to experience navigating an inaccessible setting. Over 40 students were present and were able to ask questions about Spina Bifida, SBANENY and how to get involved. **Do you know a school/setting that would benefit from a Spina Bifida training? Contact SBANENY! We present at no charge virtually and in-person. (admin@sbaneny.org).**

NYS Assembly Hearing on Employment for People with Disabilities

On 10/20/2021, SBANENY spent the day at the NYS Assembly Hearing on Employment for People with Disabilities and testified on behalf of the Spina Bifida community. In NYS, less than 35% of people with disabilities are employed compared to those without disabilities (over 75%). NYS is also ranked 41st in the country for employment rates for people with disabilities. Thank you to everyone who contributed their personal and professional expertise to be utilized in our testimony. You can still submit a testimony to your representative and Assemblymembers Abinanti, Joyner, and Burdick to share what you think needs to change in NYS to support employment for people with disabilities. <https://nyassembly.gov/mem/search/>



Virtual Programs

Funding Strategies for Assistive Technology with Tech Works

- ◆ What happens when the assistive tech you need isn't covered by your insurance? SBANENY was joined by Tech Works Representative Mary who shared tips and tricks for funding assistive tech! Click [HERE](#) to watch the recording.

Consumer Directed Choices Live Q&A

- ◆ SBANENY was joined by Denise Dinoto from Consumer Directed Choices where we talked all things CDC! Topics covered include: what CDC does, how to access services, personal care services, fiscal intermediaries, and more! Recording will be available on our YouTube soon. Announcement will be made via social media once posted.

Ask the Adult with Heather Horwedel

- ◆ **Recording now available!**
- ◆ Heather Horwedel, an adult with Spina Bifida, joined us to discuss her experiences with system navigation, self advocacy, housing, and becoming independent! Click [HERE](#) to view the recording.

SBANENY Program Updates

Awareness Month Photo Project

This Awareness Month we asked you to help us change the narrative around disability by submitting an image and 1 word you use to describe yourself! We wanted to combat negative language used to discuss individuals with disabilities and remind the public that **people with Spina Bifida are people!** If you did not get a chance to submit a photo, click [HERE](#) to create one!



SBANENY Merchandise Design Contest Winner

Designed To Be Loved

SBANENY launched our first merchandise contest in September to launch this Spina Bifida Awareness Month. Congratulations to Marcos Taveras and his “Designed To Be Loved” Apparel now available at SBANENY’s online apparel store.

Click [HERE](#) to visit our online store and purchase yours today!



SBANENY receives the NY Mets Team Spirit Award

SBANENY Executive Director and Board of Directors take the field to receive the Team Spirit Award on Spina Bifida Awareness Day at Citi Field. Thank you NY Mets!



SBANENY Welcomes 3 New Interns

SBANENY Intern

Welcome McKayla Dias! McKayla joined our Employment Training Program in August, and has helped the office with important projects like outreach, mailings, filing and more! We are so happy to welcome her to the SBANENY Team!

Master of Social Welfare Interns

- Bri Darnell:** Bri holds a Bachelor's degree in Psychology from Grove City College and has been living in Albany for the past three years working as a resident assistant in a residential Substance Abuse Recovery program.
- Leni Ferner:** Leni is a recent graduate of Plattsburgh State with a bachelors in Social Work and moved to Albany this summer to begin the Advanced Standing Masters of Social Work program at UAlbany!

Bri and Leni will be working with SBANENY to support our individual and family services until May! If you have questions for either Bri or Leni, you can reach them at: socialworkintern@sbaneny.org



DARE TO DREAM

with SBC&NENY



November 20th, 2021

Live Event: 6:00 pm

Virtual Ceremony: 7:15pm

Wolferts Roost Country Club,
Albany, NY 12204



Live & Silent Auction
Appetizers, Dessert & Live Music



Honorary Chair: Dr. Dennis McKenna, Albany Med CEO & President

You Make a Difference Award: The Daily Gazette of Schenectady



**NORTHEASTERN
NEW YORK**

Dare to Dream Sponsors

SOCHA PLAZA



LET'S GET *moving*

The Chamberlains



Honorary Committee

Two Star

Rich and Terri Sleasman

Crystal and John Hoey

Dave and Karen Wentworth

First New York Federal Credit Union

Shining Star

Amy M Aldrich

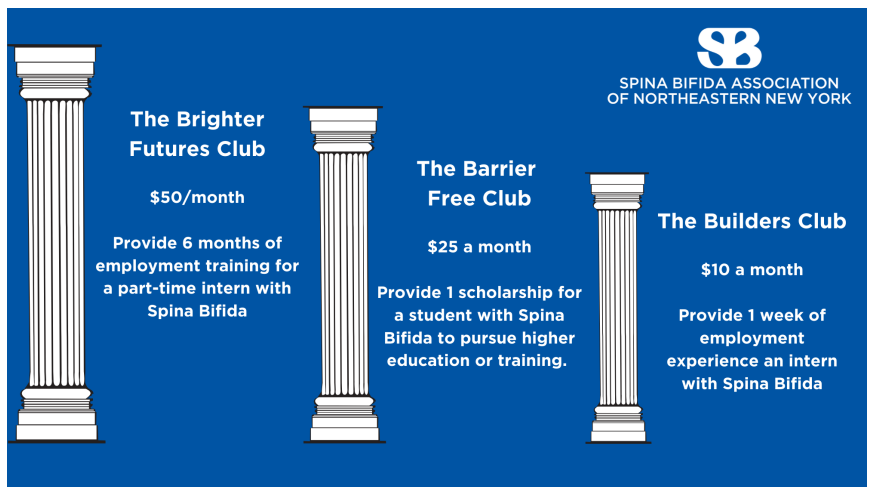
Ways to Give

THE COLUMN

Join SBANENY's Monthly Giving Society

What is The Column? A community of supporters who are the foundation to building a better and brighter future for all those impacted by Spina Bifida. We invite you to further your impact by joining The Column and ensuring individuals and families living with Spina Bifida receive stable and consistent support!

[Sign up today!](#)



SB
SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK

Club Name	Monthly Amount	Benefit
The Brighter Futures Club	\$50/month	Provide 6 months of employment training for a part-time intern with Spina Bifida
The Barrier Free Club	\$25 a month	Provide 1 scholarship for a student with Spina Bifida to pursue higher education or training.
The Builders Club	\$10 a month	Provide 1 week of employment experience an intern with Spina Bifida

THE CHANGE JAR

SBANENY now offers a round-up program! By joining The Change Jar, when you do your shopping, the transaction is rounded to the nearest dollar. The spare change collected is then donated to SBANENY at the end of each month.

Upon signing up, you can set a maximum “round-up” amount starting at \$10.00 each month. Don't worry! Your spare change will not exceed your set monthly round-up amount!

This program is secure, private, and user-friendly. Change Jar members can easily access their account, monitor what transactions are rounded up, and adjust the maximum round-up amount.

Text SBANENY to 26989 to sign up today!

Your spare change = big change!



Smile with SBANENY: Donate Using Amazon Smile

You can donate to SBANENY every time you make an Amazon Purchase!

AmazonSmile is a program that donates 0.5% of your eligible purchases on Amazon to a charity of your choice. All you need to do is start your shopping at smile.amazon.com and choose the Spina Bifida Association of Northeast New York. The donation will be made at no extra cost to you!

Smile While You Shop!



Use Amazon Smile to Support SBANENY this #SpinaBifidaAwarenessMonth

Click [HERE](#) to visit Amazon Smile and select

The Spina Bifida Association of Northeastern New York as your non-profit of choice!

NEWS TO USE

SBANENY Case Manager will now be at the Albany Med Spina Bifida Clinic!

SBANENY Case Manager, Conlee Deleonardis will now be attending the monthly Spina Bifida Clinics. Conlee provides individual and family services, she is available for support, advocacy, systems navigation, referrals, education, and more! Schedule your clinic appointments and come say “hi” to Conlee starting November 9th! If you have questions about the clinic or would like to learn more:

Email: casemanager@sbaneny.org / **Phone:** 518-399-9151 / www.amc.edu/spinabifida.

SBANENY UPDATES

SBANENY: Program Feedback Survey

- **Complete this survey before 11/7 for a chance to win a \$50 gift card!** SBANENY is seeking feedback about our programs and services, your feedback will be used to develop future programs and ensure that we are serving our community is the best way possible! Click [HERE](#) to complete the survey and enter the raffle! Winner will be announced via social media at the end of November.

COVID-19

COVID-19 Family Discussion with the DDPC

- Join Dr. Rivelis and Dr. Bernstein as they discuss how to navigate thoughts and feelings that arise for children, teens, and adults with developmental disabilities and their families relating to COVID-19. Thursday, November 4th @ 7:30PM. Click [HERE](#) to learn more!

COVID-19 Vaccine: Third Booster Shot Information

- The CDC is recommending COVID-19 booster shots for certain individuals to protect against the Delta Variant. If you received the Pfizer vaccination, and would like to see if you qualify, click [HERE](#) to learn more!

Disability-Specific COVID-19 Federal Guidance

- The Council of State Governments updated its policy brief on "COVID-19 Federal Disability-Specific & Other Related Guidance." The brief outlines federal guidance on COVID-19 and people with disabilities to help states and localities ensure their policies follow civil rights laws and other disability-related policies. Click [HERE](#) to learn more

EMPLOYMENT

Employment Opportunities at The ARC

- The ARC of Washington, Warren, and Albany Counties has multiple career opportunities available! Click [HERE](#) to learn more!

Inclusively: Employment Opportunity Search Engine

- Looking for your next career opportunity? Inclusively is the technology-centered inclusion solution and employment platform for job seekers with disabilities, mental health conditions, and chronic illnesses. Click [HERE](#) to make an account!

Employment Opportunities at the Center for Disability Services (CFDS)

- CFDS is hiring for multiple positions! Click [HERE](#) to explore open positions and apply online

SBANENY SCHOLARSHIPS

SBANENY: Technology Scholarships Available!

- Apply for financial assistance for technology and related supports to improve your access to virtual opportunities including school, telehealth, online programs and more!

Frank Bucino Jr. Memorial Scholarship

- Conference attendance, higher education and/or technical training for individuals with Spina Bifida

Helen R. Mertens Educational Scholarship

- Higher education, technical training, or driver's education for individuals with Spina Bifida

To learn more click [HERE](#) !

180 Medical College Scholarship

- 180 Medical offers scholarships for caregivers and students with disabilities. Scholarships are open to full time students living with specific medical conditions, including Spina Bifida. Applications are accepted from January 1 to June 1st each year. Click [HERE](#) to learn more and apply.

NEWS TO USE

LOCAL PROGRAMS AND EVENTS

ILCHV Fall Wellness Classes

- The ILCHV has released it's fall virtual wellness calendar! *Classes are free and include: wheelchair dance with Ania, mindfulness, cooking, yoga, Pilates, art therapy, nutrition and much more!* View the program [HERE](#). To register, click [HERE](#) or call the ILCHV at 518-2274-0701

Guilderland Public Library Fall Event Calendar

- The Guilderland Public Library has released it's program calendar for fall including Halloween themed arts and crafts, Thanksgiving card prep, as well as winter and fall themed card nights, and more! Click [HERE](#) to view the calendar and learn more about the different activities!

Hunter Ways Farm: 2nd Annual October Festival

- A free family fun event - free games and activities for the kids, with food vendors (Czechs Hot Dog Wagon, Cotton Candy, Caramel Apples, Kettle Corn, and baked goodies), local craft vendors, trick or treating, Halloween Costume Contest and more! Activities at the event include: pontoon boats, interpretive hikes, adaptive fishing clinic, camping demonstrations, and more!
- October 30th, 10am — 4pm! Events:
 - Vendor sales 10am to 4pm
 - Trick or Treating 3pm to 3:30pm
 - Halloween Costume Contest 3:30pm to 4pm
- Click [HERE](#) to learn more!

ADVOCACY

The ARC: Tell Congress to Pass the Better Care Better Jobs Act

- Join the ARC's campaign to push Congress to pass the Better Care Better Jobs Act!
- The Better Care Better Jobs Act includes a long-overdue investment in the disability service system as part of a COVID-19 economic recovery to support care for Medicaid recipients and create more and better jobs for the workforce that provides that care.
- Click [HERE](#) to take action and sign up for future advocacy alerts from the ARC

Fair Pay from Home Care Workers

- Home care workers are a vital part of our community. Join the advocacy campaign to encourage Governor Kathy Hochul to pass the Fair Pay for Home Care Workers Act which encourages employers to pay home health aids a fair wage, securing accessible, dignified care for older adults and disabled people. Click [HERE](#) to get involved!

The Self Advocacy Association of New York State (SANYS) Statewide Virtual Conference

- SANYS is holding its Virtual Self Advocacy Conference on December 9th, 10th, and 11th! The theme for this year will be: Stronger Together. More details to follow, click [HERE](#) to sign up for updates!

Youth Leadership Forum and Foundations for Leadership In Person Event!

- AMPLIFY-NY is hosting in-person Youth Leadership Forums (YLF) for young people ages 14-24 to speak up, build leadership and self-advocacy skills, and prepare to take on leadership roles.
- They will also be hosting a new and expanded in-person Foundations for Leadership training for parents and caregivers, who are now also welcome to attend along with their youth/young person. The training is designed by parents for parents/caregivers to learn strategies and gather skills for supporting your youth/ young person as they grow into leaders and transition into adulthood.
- Upstate - November 11-14. Register for the trainings [here](#).

Long Term Care Community Coalition (LTCCC): 12th Annual Reception

- The LTCCC will be hosting its 12th annual reception (in person) on Tuesday, November 9 from 6-8pm (ET). This years Reception will be dedicated to New York State Attorney General Letitia James and feature a presentation by Carmen Bowman on practicable ideas for changing the culture of nursing homes. Plus: a mini-concert!
- NY City Bar, 42 W. 44th Street, NYC. Registration Fee: \$200 (\$150 for non-profit consumer organizations) Click [HERE](#) to learn more

SOCIAL SECURITY

The October Edition of The Social Security Star

- The SSA's monthly newsletter is out! Topics covered in this month's issue include: Protecting Your Social Security Card, The Launch of the New Online Form Submission Portal, and more. Click [HERE](#) to read!



SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK

ABOUT SBANENY

***Mission:** To build a better and bright future for all those impacted by Spina Bifida.*

***Vision:** We envision a world where everyone impacted by Spina Bifida is accepted and thrives.*

Our purpose is

***S**upport*

***H**ealth & Wellness*

***A**wareness*

***R**espect & Dignity*

***E**mpowerment*

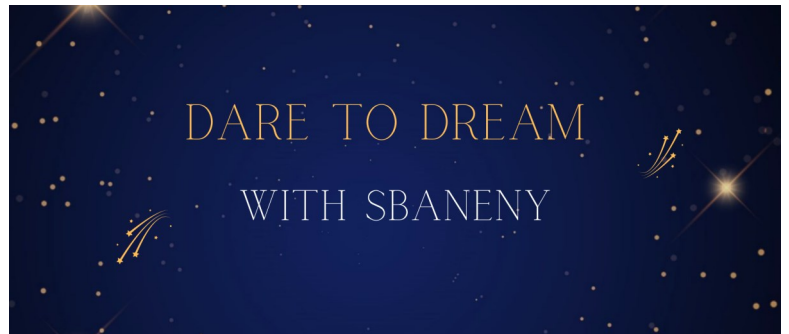
UPCOMING EVENTS!

Dare to Dream

November 20, 2021

Express Feedback for Good

December, 2021



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

Dare to Dream— November 11, 2021

Development—October 27, 2021

Governance - November 9, 2021

Board of Directors— November 13, 2021

COMMITTEES TO JOIN

Conference

Dare to Dream

Walk-N-Roll

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.