



SBANENY Newsletter

WELCOME LETTER

Happy Spring,

Let's hope that the snowflakes are behind us and many flowers are ahead. You might have heard that Spina Bifida is known as the snowflake condition. There are some commonalities between those who are born with Spina Bifida, but it presents itself in so many different ways that it has a unique impact on everyone affected. Two of the commonalities are a "can do" attitude and a desire to support each other.

This winter has been extremely busy and successful for the Spina Bifida Association of Northeastern New York (SBANENY). We teamed with the Spina Bifida Association of Greater New England to host the "Strut and Stroll: Fashion Show For All". Models from both chapters and designers from across the country participated. It was so amazing to hear the stories of every designer, each faced with a challenge, and their designs that addressed those challenges in attractive and fashionable ways. The solutions included comfortable and warm clothing for those who utilize wheelchairs and shoes that can be purchased individually because of different sized feet. It was a powerful and extremely uplifting presentation.

We just recently completed our virtual Conference, which was planned by a remarkable team of committed individuals. Titled "Empowerment Through Knowledge", it contained presentations from doctors in the fields of Urology, Neurosurgery, and Orthopedics. Another commonality of Spina Bifida is the need to routinely see doctors from multiple fields and specialties. All the physicians in our Conference are part of the team of doctors at the Spina Bifida Clinic at Albany Med.

SBANENY does what it does to meet the needs in our community. It is very nice however to be recognized by one's colleagues. Recently SBANENY received a Chapter Award for Outstanding Programing for Adults from the national Spina Bifida Association (SBA) for our monthly zoom meetings for adults living with Spina Bifida. In addition, our Executive Director Julia Duff received the national SBA Thomas Baroch Advocacy Award for outstanding advocates on the national and/or state level. This award is "presented annually to an individual who have had a significant and lasting impact on advocacy for research and other policy issues affecting the lives of people with Spina Bifida."

We invite you to join our team in the pursuit of knowledge and support. Please look through this newsletter for some of our other programs, as well as opportunities to help out in a variety of different ways. We especially want to draw your attention to our Bottle and Can Drive (4/22/21 through 5/15/21) and our virtual Walk-N-Roll on May 15th. Check out our website: www.sbaneny.org for more details. 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.

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APRIL 2021

WELCOME LETTER

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NEWS TO USE

SBANENY GIVING

WAYS TO GET
INVOLVED

SBANENY BOARD

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Julia Duff

Advocacy Updates

SBANENY typically receives no public funding, relying on donors, fundraisers, and grantors to provide individual and family programs and services. For over a decade, we have provided education to the NYS Legislature on Spina Bifida and for the past five years, requested funding to more effectively serve the estimated 10,000 individuals living with Spina Bifida in our state. This year, we met with nearly 30 Assembly members and Senators to raise awareness about Spina Bifida, SBANENY, and what NYS can do to support this community. We are so grateful to the advocates, volunteers, individuals and families as well as NYS representatives and staff persons who have participated in these efforts. We are pleased to announce that SBANENY has been included in the recently passed NYS budget. This financial support will have a huge impact on individuals and families living with Spina Bifida in our state!



National SBA's 2021 Virtual Teal on the Hill: March 1-5th 2021

This year's virtual Teal on the Hill was a huge success! **Advocates from 37 states and the District of Columbia had over 80 meetings with Congressional staffers.**

Advocates asked for a \$2 million increase for the National Spina Bifida Program at the Centers for Disease Control and Prevention, bringing the total to \$9 million. Advocates also asked Congress to support funding for the disability community as part of COVID relief legislation, which was passed March 12.



Co-chairs of the Advocacy Committee, Megan Sorensen and Will Dickey presented the Tom Baroch Advocacy Award, given in Tom's honor. Tom was a tireless advocate for those with Spina Bifida and an inspiration to all of us.

This year's awardees were Jay Dashefsky and SBANENY's Executive Director, Julia Duff !

Julia was recognized for her robust state advocacy program, assistance in reestablishing the Albany Med Spina Bifida Clinic that had been closed for over 25 years, and her commitment to advocacy.

Click [HERE](#) to read more about SBA 2021 Teal on the Hill!

You can still participate! Click [HERE](#) to Tell Congress to Increase Funding for the National Spina Bifida Program

SBANENY Program Updates

Sweat with SBANENY & SBAGNE: 30-Day Wellness Challenge

SBANENY & SBAGNE completed a 30-Day Wellness Challenge from 2/15/2021-3/15/2021. Heather Horwedel, our grand prize winner and adult with Spina Bifida, shares about her experience. See below!

"My name is Heather Horwedel. I am a 32 year old adult living with Spina Bifida in upstate New York. In February and March 2021 I participated in the Sweat with SBANENY & SBAGNE 30-Day Wellness Challenge.

This challenge has helped me a lot in many areas of my life and is something I am continuing after the challenge. The program was great in so many ways; the check-lists made it easy and brought up different areas of health that I may not pay as much attention to as I should. The virtual meeting and classes offered different opportunities that made it easy and possible (especially during the pandemic) to try things I

might not otherwise. Additionally, after recovering from a recent surgery, I needed to get back into certain healthy activities. The program offered a support community to stay motivated, bounce ideas off each other, and connect with others in the Spina Bifida community.

I was also introduced to meditation and chamomile tea neither of which I have done before and I now use daily. This has helped greatly in lowering my blood pressure over the last 3 weeks and assisting in my recovery from a recent surgery. This challenge taught me to learn how to track calories and where I needed to change my eating habits. Lastly, I've realized how much I need to slow down and take more time for me. This has brought me back to a hobby I used to love but in recent years have not made time for; painting which I have decided to continue to do gives me another way to keep busy during the pandemic and I am now using this as a way to give back. Overall, this was a very positive experience and given the chance I would participate again."



Hannaford.



CELSIUS
LIVE FIT

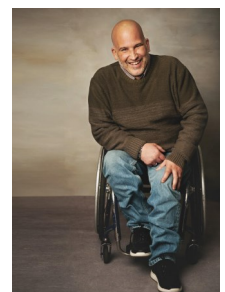
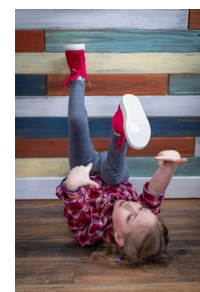
Check out our free wellness sessions: Seated Pilates, Dance with Ania, Nutrition Webinar, Mindfulness with Lauren, and Fit With Amy B Family Class available on our [YouTube Channel](#)!

Strut & Stroll: Fashion Show For All

On March 25th, SBANENY and SBAGNE teamed up to present the first ever Spina Bifida Adaptive Fashion Show! The Fashion Show featured items from: **Bold Body, Billy Footwear, IZ adaptive, Juniper, Magna Ready, Patti +Ricky, Punkin Futz, Runway of Dreams, Stride Rite, Slick Chicks, UNITEABLE, Tiny Superheroes, Yarrow, and Zappos Adaptive!**

The night wrapped up with a very productive discussion about adaptive fashion, its future, and how we can continue to become more inclusive in this industry. SBANENY would like to thank all our fabulous models who rocked the runway! We would also like to thank our round table participants, who had a dynamic discussion about the future of fashion.

If you were unable to attend the presentation click [HERE](#) to access the recording!



SBANENY Events Calendar

SBANENY Virtual Conference

Empowerment Through Knowledge: Living with Spina Bifida

4/17/2021

If you were unable to attend, you can still access the 2021 Virtual Conference session materials and recordings for \$15.00.

Make a one time donation to our Conference campaign, and SBANENY will send you the slides and recordings.

Click [HERE](#) to access the Conference.

Check out our [Sponsor & Vendor Video](#) featuring product and service updates from Albany Med, Mobility Works, 180 Medical, Consumer Directed Choices, Beyond My Battle, Koolway Sports, Canine Companions for Independence, Juniper Unlimited, Mental Health Association of NYS, Center for Disability Services, Team Impact, and Inclusively.



Virtual Walk-N-Roll for Spina Bifida May 15th 2021



THEME: THE POWER OF YOUR VOICE

Why? Because there is power in numbers! Although we cannot gather with hundreds of Spina Bifida friends and families this May, we can still receive connections, support, and feel empowered by the Virtual Walk-N-Roll!

How? By sharing your story!

Individuals and families with Spina Bifida advocate on a momentary to daily basis. Whether it is raising awareness about inaccessible venues, conducting research on Spina Bifida so you or your child can receive quality medical care in appointments, using people-first and empowering language when discussing disabilities, or meeting with governmental agencies to advocate for equal access... the fight is ongoing. SBANENY aims to raise awareness about the every day advocacy being done by our community so we can highlight changes that can be made to create a more inclusive society. **The best part?** You could win a gift card by participating! All individuals and families who submit an image and share a story about what YOU advocate for will be entered into a raffle for a \$50.00 gift card. Submissions due by May 3rd and will be incorporated into an awareness video shared on social media on May 15th, the day of the Virtual Walk-N-Roll.



Session 1: Urological Updates and Spina Bifida Clinic Care, 9:05am EST

Dr. Alex Rehfuss, AMC

Session 2: Neurosurgery and Spina Bifida, 10:30am EST

Dr. Matthew Adamo, AMC

Lunch Hour & Vendor Video Display, 12:00pm EST

Session 3: Mindful Stress Management for Chronic Conditions, 1:30pm EST

Martel Catalano, Beyond My Battle CEO

Session 4: Orthopedic Impact and Treatment Across the Lifespan, 3:00pm EST

Dr. Vivek Dutt and Dr. Abigail Mantica, AMC



Virtual Walk-N-Roll for Spina Bifida Pre-Event & Day of Activities

Legislative Advocacy Q&A

Wednesday, April 28th at 5:30pm EST via Zoom

Featured speakers: Donna Jones and Julie Yindra

[REGISTER HERE](#)



Debunking Disability Myths

Wednesday, May 12th at 5:30pm EST via Zoom

Featured speakers: Anya Kewley and Sonja Baker

[REGISTER HERE](#)

Bottle & Can Drive

Thursday April 22nd—Saturday May 15th

We are accepting donations of recyclable bottles and cans from now > May 15th. All proceeds raised will support the programs and services benefitting individuals and families living with Spina Bifida!

You can participate by -

- Bringing your bottles and cans to the SBANENY office on May 15th between 9:00am and 3:00pm
- Pick up Hannaford CLYNK bags and tags and donate the cost of your recyclables to SBANENY
- Host a 3rd party bottle & can drive where you are and contribute the funds raised to SBANENY

Questions? Contact Julia Duff at admin@sbaneny.org or 518-399-9151.



Online Auction

Saturday, May 1st @ 7:00pm — Sunday, May 23rd @ 12:00pm

In conjunction with our annual Walk-N-Roll for Spina Bifida (virtual again this year), we are offering an online auction, in lieu of our usual basket raffles. You can bid for free but registration and logging onto the bidding site is required! Visit [the bidding site](#) to check out over 10 baskets and register today!

\$100 Walk-N-Roll T-Shirt Pick-Up Day

Saturday May 15th, 9:00am-3:00pm

SBANENY office (123 Saratoga Rd, Scotia, NY 12302)

Drop off your recyclables, purchase some of Annmarie's "famous cookies," and pick up your \$100 Walk-N-Roll T-Shirt all at once! Recipients can either receive their own latex-free tie dye kit or a pre-tie dyed shirt.



PRESENTED BY:



VIRTUAL WALK-N-ROLL FOR SPINA BIFIDA



ALL PROCEEDS BENEFIT THE
PROGRAMS AND SERVICES OF:



SPINA BIFIDA ASSOCIATION
OF NORTHEASTERN NEW YORK



SATURDAY MAY 15TH

Join the Spina Bifida community by completing
a family-friendly 1 mile walk or roll on 5/15/2021!

REGISTER AT WWW.SBANENY.ORG!

SBANENY is a nonprofit
serving individuals and
families living with Spina
Bifida. Your donations benefit
those we serve and are tax
deductible!

Help the Spina Bifida Association of Northeastern New York (SBANENY)
build a better and brighter future for all those impacted by Spina Bifida!

- Register to walk or roll on Saturday May 15th
- Wear teal to raise Spina Bifida awareness
- Participate in contests, an online auction, and pre-event programming
- Become a sponsor or corporate partner

Contact Julia Duff at
518-399-9151 or
admin@sbaneny.org
with questions!

Thank you to our sponsors!



SBANENY GIVING

THE COLUMN

Join the Spina Bifida Association of
Northeastern New York's (SBANENY)
monthly giving society, The Column



The Brighter Futures Club

\$50/month

Provide 6 months of employment training
for a part-time intern with Spina Bifida

- Receive an invitation to a 30 minute meet & greet with SBANENY staff
- Monthly impact reports
- SBANENY's on-boarding basket with a poster, merchandise, newsletter, welcome letter and certificate
- 50% discount on individual attendance fees to SBANENY events



The Barrier Free Club

\$25/month

Provide 1 scholarship for a person with
Spina Bifida to pursue higher education
or training

- Receive biannual impact reports
- SBANENY's on-boarding basket with merchandise, newsletter, welcome letter and certificate
- 20% discount on individual attendance fees to SBANENY events



The Builders Club

\$10/month

Provide critical healthcare information
and resources to 1 individual/family
each month

- Receive annual impact reports
- SBANENY's on-boarding basket with a newsletter, welcome letter and certificate
- 10% discount on individual attendance fees to SBANENY events

A special feature of The Column is our Change Jar!

THE CHANGE JAR

Your spare change = big change!

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.



*Give without
thinking twice -
It makes cents!*

Check out all of our 2021 sponsor
opportunities at www.sbaneny.org

SBANENY Day at NY Mets Stadium!



Keep an eye out! SBANENY
will be selling tickets to a
NY Mets Game we will be
attending this August!

NEWS TO USE

SBANENY PROGRAMS -

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!
- To learn more click [HERE](#) !

Employment Training Program

- **The application period for the Employment Training Program closes May 15, 2021.**
- Working age individuals with Spina Bifida can apply to gain employment skills through a part-time paid internship program at SBANENY.
- To learn more click [HERE](#) !

EQUIPMENT AVAILABLE!

Scooter—

A family in Albany, NY has offered to donate the scooter in the picture provided to an individual and/or family living with Spina Bifida.

If you are interested, contact SBANENY at admin@sbaneny.org / 518-399-9151.



Continence Supplies—

- 2 - Abena - Abi-San Premium X28
 - 1 - DMI - Incontinent pants - M
 - 6 - Abena - Abi-Form L4
 - 1 - Depends - Protection Plus - under wear
 - 2 - Medline - Contour Plus - Bladder pads
 - 1 - Sterile - leg bag
 - 3 - Depends for men Max - 3 packages @ 85
-

Oscar Spotlight: “Crip Camp” Roundtable Discussion

- Nominated this year for an Academy Award® in the category of best documentary feature, “Crip Camp: A Disability Revolution,” follows the birth of the disability rights movement. The film starts in 1971 at Camp Jened, a camp for teens with disabilities and focuses on how those campers become activists in their fight for accessibility legislation. Washington Post film critic Ann Hornaday spoke with the film’s directors, writers and producers Nicole Newnham and Jim LeBrecht. Click [HERE](#) to watch!

Office for People with Developmental Disabilities

- Beginning April 2021, OPWDD will begin offering virtual front door sessions via WEB EX. Attendees may register for any session, regardless of where they reside. Attendees can simply pick the date and time that works best for them and follow the instructions to register.
- The Information Session schedule and registration information may be found on the [OPWDDs Information Sessions Page](#).
- Presently, all April 2021 sessions have been posted, future sessions will be added soon. .

NYS Special Education Task Force presents the 22nd Annual Virtual Conference

Beyond Surviving: The Road to Thriving for Students with Disabilities in a Post-Pandemic World

- This event is free to attend. Keynote and concurrent workshop sessions are intended for all stakeholders including parents, students, school personnel, advocates, and providers. The goal of all sessions is to inform and inspire communication to increase educational outcomes for students with disabilities
- Friday April 30th 9:00 am—4:00 pm
- Questions? Contact: mail@nyspecialtaskforce.org

The Butt Stops Here: FREE Course to Quit Smoking!

- Free Virtual Smoking Succession courses are available for spring and summer! You do not have to quit smoking prior to the start of the course!
- Classes have been added for April, May, June:
 - Tuesdays at 7 pm, beginning May 4
 - Mondays at 4 pm, beginning June 7
- Click [HERE](#) to register!

Special Needs Planning Webinar, Monday 5/3 @ 12

- Topics covered include an overview of SSI & SSDI, Medicaid & Waivers, ABLE accounts, special needs trusts, and other important considerations to help family members better understand how planning for a child with special needs is different both legally & financially.
- <https://attendee.gotowebinar.com/register/550274098277419533>

NEWS TO USE

Program News

Double H Ranch Update

- Double H Ranch will be welcoming campers back onsite for a residential 2021 Summer Camp Program at 30% capacity. For more information, click [HERE](#).

Move United

- Move United uses the power of sport to push what's possible for people with disabilities, confronting ignorance, fueling conversation, and inciting action that leads us to a world where everyone's included. GET YOUR FREE SUBSCRIPTION TO MOVE UNITED MAGAZINE [HERE](#)!

Lifeline Federal Benefit for Medicaid users.

- Lifeline is a federal benefit that lowers the monthly cost of phone or internet service. Check out if you qualify [HERE](#) and start saving today!

Employment News

Job Accommodation Network

- JAN will be hosting a webcast on May 20th for Global Accessibility Awareness Day! Accessibility & Accommodations: How Employers & HR Professionals Can Prepare for Emerging Tech in the Workplace. JAN is co-hosting this session in collaboration with the Partnership on Employment & Accessible Technology (PEAT).
- Taking place on May 20th at 1pm, click [HERE](#) to register

Office of Disability Employment Policy (ODEP)

- Participate in an online dialogue facilitated by the US Department of Labor to share your ideas on how to ensure racial and social equity in employment policies and programs for people with disabilities from historically underserved communities.
- Click [HERE](#) to participate!

Southern Tier Special Education Task Force is hosting a Teaching and Helping Special Needs Youth Webinar, May 5th, 1:30pm

- From the Task Force: Whether it's in the classroom or at home, sometimes children receiving special education can really try our patience. If we understand more about where they are coming from emotionally, we might be able to help. If we understand more about ourselves when interacting with youth with disabilities, we can definitely help them! In this workshop, learn about mental health & how it manifests in people's behavior.

- This webinar will focus on ways to become self-aware, with the goal of improving our interactions with the children we work with, whether we are professionals at schools or parents/guardians at home.
- Click [HERE](#) to register!

COVID-19 News

New York State: COVID Vaccine Expanded Eligibility

- New York State has now expanded the eligibility requirements for the COVID-19 Vaccine to include individuals aged 16 and up
- To schedule a vaccine, click [HERE](#). You can also schedule an appointment over the phone, by calling 1-833-NYS-4-VAX (1-833-697-4829).
- If you have questions about the COVID-19 Vaccine, SBANENY encourages you to reach out to your primary care provider to ask if the COVID vaccine is right for you.

The CDC: One Stop Shop Tool Kit for COVID-19

- The Centers for Disease Control and Prevention (CDC) offers a COVID-19 One-Stop Shop Toolkit for people with disabilities. Check out the [Toolkit](#) for guidance and tools to help people with disabilities and those who care for them to make decisions, protect their health, and communicate with their communities.
- Resources within the toolkit include:
 - COVID-19 Vaccine Resources
 - Guidance and planning documents
 - Web resources
 - Poster, Videos, and Social media
- For further information, please contact DHP@health.ny.gov.

COVID-19 & Media Survey

- Do you have a child with a disability between the ages of 5 and 13 years old? And do they have a sibling ages 5 to 13 without a disability? Researchers at the University at Albany and Northeastern University are looking for parents to take a brief 10-minute survey. You must be 18 or older and live in the United States.
- The goal of this survey is to help us learn how parents have managed their children's media use during the COVID-19 pandemic. Participation in this study is completely voluntary and all information is kept confidential. **When the study is done, 4 parents will be randomly selected to win a \$100 Amazon gift card.** Click [here](#) to see if you are eligible and to take the survey.



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!

Legislative Advocacy Q&A

April 28, 2021

Debunking Disability Myths

May 12, 2021

Virtual Walk-N-Roll for Spina Bifida

May 15, 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— May 5, 2021

Development—April 25, 2021

Governance - May 4, 2021

Board of Directors— May 22,, 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.