



SBANENY Newsletter

WELCOME LETTER

Happy Summer Everyone,

I hope that this newsletter finds you enjoying some beautiful summer weather with your family. At the Spina Bifida Association of Northeastern New York (SBANENY) we are looking forward to August 1st. The New York Mets are honoring SBANENY at their 1:10 pm game against the Cincinnati Reds, for the work that we do supporting families and individuals with Spina Bifida. We are absolutely honored and invite you to join us. Please go to our webpage (www.sbaneny.org), and click on the link to order tickets for \$40 each. We would love to share the event, and the singing of "Take Me Out to the Ballgame" with you!

Whether you can come to the game or not, you can support SBANENY by going to our first online store (<https://willpromo.com/sbaneny/shop/home>) and purchase SBANENY clothing and/or caps. The link is at our webpage (www.sbaneny.org) for you to click. We are planning on expanding our offerings with a merchandise design contest in the next few months where you can submit a design to be featured on SBANENY items. Board member, Paul Lukasiewicz III is pulling together some of the final details. You might remember Paul as the designer of the "I Love Someone with Spina Bifida" t-shirts. Stay tuned for our upcoming announcement about it.

On May 15th we had a very successful virtual Walk-N-Roll event. This is one of our major fundraising events during the year. This year we were able to include an online auction and a bottle drive to help the proceeds. Everyone who raised at least \$100 was given a Walk-N-Roll tie died t-shirt. We hope that in the future we can have an in person Walk-N-Roll, because we love when everyone can get together and share successes and ideas.

You might ask what we do with all of the monies raised at our various events? Every summer we put out an Annual Report where we explain the many different ways in which we support individuals and families with Spina Bifida. Our Annual Report is available inside this newsletter and at the SBANENY webpage. Watch for it and get a feel for all that we do. We hope that you will learn more about us, what we do, and the difference we make in people's lives.

One of these ways is our Employment Training Program where we hire a couple of individuals with Spina Bifida as interns. Our goal is to provide employment experience and skills in an office setting, with guidance and support. We benefit from some extra hands in the office helping with the work, but the real purpose is to allow our interns to grow in their understanding and confidence in a real work place.

How would you like to join us? We are able to accomplish a lot with the help of many volunteers. Take a look at our webpage (www.sbaneny.org), and click on the link on the left, where we explain the various different ways that you can help us. I promise that we will find a way to include you in what we do and help you feel more fulfilled.

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 #86
JULY 2021

WELCOME LETTER

SBANENY WALK-N-ROLL

SBANENY PROGRAM UPDATES

SBANENY EVENTS

DARE TO DREAM

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 Walk-N-Roll Presented by The Daily Gazette

Thank you to all of our 2021 Virtual Walk-N-Roll participants! Thanks to our generous donors, **SBANENY raised \$12,500!** This funding allows us to continue pursuing our mission of building a better and brighter future for all those impacted by Spina Bifida.

Our virtual auction raised \$300 and featured amazing items like artwork, gift cards, crafts, and activity baskets.

Highlights from this year include visits from **Assemblymembers Phil Steck and Mary Beth Walsh**, our new tie-dye Walk-N-Roll t-shirts, a bake sale by Annmarie Fennicks, and Heather's handmade jewelry and paintings!

Thank You To Our Hard-Working Committee Members:

Michelle Miller (Co-Chair), Heather Horwedel (Co-Chair), Kevin Chamberlain, Joe Slaninka, Megan Smith, Paul Lukasiewicz III, Peggy Smith, Pauline Cassillo



Our bottle drive raised \$400 with over 50 bags of bottles collected!



Thank You To Our 2021 Walk-N-Roll Sponsors

The Daily Gazette, Mobility Works, Consumer Directed Choices, Bussani Mobility, Cap Com, and MVP!

THE **DAILY**
GAZETTE
dailygazette.com



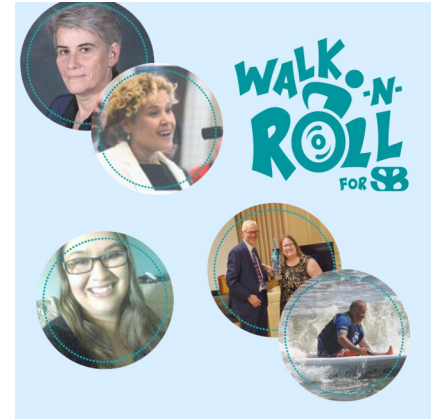
MVP[®]
HEALTH CARE

SBANENY Program Updates

Walk-N-Roll Theme: The Power of Your Voice

As a part of our Walk-N-Roll theme, SBANENY hosted a 3-part advocacy series featuring adult speakers living with Spina Bifida.

1. **Legislative Advocacy Q&A:** advocacy experts Donna Jones and Julie Yindra talked about their experiences with legislative advocacy on a state and national level. Click [HERE](#) to watch the recording.
2. **Debunking Disability Myths:** featured advocates Sonja Baker and Anya Kewley discussed their journey with self-advocacy and combatting stigma around disabilities. Click [HERE](#) to watch the event.
3. **Becoming Your Own Advocate** completed the series with Lyndsi Holmes-Wickert and Joe Slaninka who discussed tips for becoming more comfortable with self-advocacy and encouraging children to become self-advocates! Click [HERE](#) to watch the event recording.



Hear From Heather Series

During the weekend of the Walk-N-Roll, SBANENY shared three stories on [Facebook](#) from Heather Horwedel, Walk-N-Roll committee Co-Chair and an adult with Spina Bifida who discussed her experiences advocating for [housing](#), [medical supports](#), and [employment](#)!

Do you have an idea for a future program or event?

Please complete our [6 month survey](#) and email your suggestions and feedback to: casemanager@sbaneny.org



Skin Integrity Program: Protecting the Skin You're In!

This June, SBANENY hosted two webinars about the importance of protecting your skin!

1. **Spina Bifida and Protecting Your Skin:** Presenters Pat Beierwaltes, DNP, C-PNP, and Jennifer Wilhelmy, ANP who assisted in the development of the National SBA *Skin Integrity Bundle: Did You Look* presented on ways to keep your skin healthy and prevent breakdown and wounds. Click [HERE](#) to watch the recording.
2. **Spina Bifida and Equipment Considerations:** Presenters Melissa Washco, C.P.O from La Torre Orthopedic Laboratory & Kelly Ulbricht OTR/L, ATP, from Numotion discussed equipment considerations for individuals with Spina Bifida and skin integrity. Click [HERE](#) to watch the recording.

Check out our other programs on our Youtube Channel: [Dance with Ania](#), [Nutrition Webinar](#), [Mindfulness with Lauren](#), and [Fit With Amy B Family Class](#) available [HERE](#)!

SBANENY welcomes Maddie Gallagher as a Summer Intern!

Maddie is SBANENY's third intern to participate in the Employment Training Program.

Maddie will be interning with SBANENY throughout the summer months to gain employment skills in a hybrid (remote and in-person) setting. *Congratulations Maddie!*



SBANENY Events Calendar

Spina Bifida Day at Citi Field

August 1st at 1:10pm, NY Mets vs. Cincinnati Reds

Join SBANENY and friends for a day at the ballpark. SBANENY will be featured on the scoreboard, receive the NY Mets Spirit Award, and be announced at the stadium. **Tickets are \$40.00 per person.** Seats are field level/left field and accessible seating is available!

PURCHASE YOURS BY 7/29/2021 @ WWW.SBANENY.ORG

TRAID Information Session

August 5th @ 5:30pm

The Technology-Related Assistance for Individuals with Disabilities (TRAID) Program provides **access to assistive technology to any New Yorker with a disability through Regional TRAIID Centers.** TRAIID provide device loans and hands-on training to people with disabilities.

Interested in learning more about TRAIID? **Join SBANENY and Justice Center Representative Melissa for a demo and Q&A all about TRAIID!** Click [HERE](#) to pre-register for the event and click [HERE](#) to submit any questions you have for our speaker.



DARE TO DREAM WITH SBANENY

Presented by Albany Med

**Live & Silent Auction Fundraiser
Saturday, November 20, 2021 at 6:00pm
Wolferts Roost Country Club**

**Honorary Chair: Dr. Dennis McKenna,
Albany Med CEO & President
You Make a Difference Award: The Daily Gazette**

WINE, CHARCEUTERIE & CHOCOLATE

Dare to Dream With SBANENY

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)
- \$25 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)

\$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 ad - \$250 Half page ad - \$125 Quarter page ad - \$ 50 Eighth page ad

2021 Direct Mail Campaign & 2020 Annual Report

This year, we asked our supporters to share with us “Why do you give?”

Population estimates indicate that 10,000 people in New York State are living with Spina Bifida. The number of people impacted by Spina Bifida, which includes caregivers and immediate and extended family, more than triples the number of people who can benefit from SBANENY services. In addition, healthcare, service providers, and others who interact with our consumers in the community also benefit from having Spina Bifida specific expertise and information available, so that they can better treat, serve, live, and work with the people living with Spina Bifida. As the primary agency specializing in Spina Bifida in New York State, SBANENY’s staff of 1 full-time Executive Director and 1 half-time Case Manager is available and serving this community. *Our programs and services would not be possible without support from the greater community.* Contributions from more than 100 volunteers who serve on committees and our board of directors, donors, corporations, and sponsors are vital as SBANENY continues to grow in reach and impact.

Meet Claudia, mom of Nicholas, a teen living with Spina Bifida. Claudia has been involved with SBANENY since Nicholas was born 18 years ago and remains involved as a program participant and supporter of SBANENY. Claudia offers peer support, occasional translation services for Spanish-speaking families, and has contributed as a donor and sponsor to SBANENY events and programs. *Here is why Claudia gives to SBANENY:*

“I give because it is a great cause. Many individuals all over the world are born with Spina Bifida including our son and they need as much support as we can give them at all stages in their lives.” – Claudia Holmok



Barb Devore is an adult with Spina Bifida. Many years ago, Barb was introduced to SBANENY when she met the former Executive Director at a nonprofit fair and learned about the available information and resources offered through SBANENY. She began volunteering and has served as a board member and on several committees. Barb assists SBANENY with responding to consumer requests for services, shares educational resources for distribution to the Spina Bifida community, facilitates programs, is a donor, and participates in fundraising events. *Why does Barb give?*

“I was born with Spina Bifida and as I age my needs change. It is important that I continue to have a source for the most up to date medical information as well as maintaining connections with peers and staff who support and encourage healthy lifestyles. SBANENY is the only organization in this region solely dedicated to the Spina Bifida community.” – Barb Devore



Mobility Works in Albany has been a corporate partner of SBANENY events including the conference and Walk-N-Roll for many years! Mobility Works not only provides financial support through sponsorships but regularly attends events with wheelchair vans and equipment for families to test out. Families can learn about specialized vehicles and equipment and receive information on potential funding resources to support these extraordinary expenses. *How do corporate sponsor partnerships benefit SBANENY and our consumers?*

“Even though Spina Bifida is only one of the many disabilities and conditions that our clients are affected by, we have seen regular clients with Spina Bifida, over the years, need our assistance. The NENY Spina Bifida Association has a local office that services folks in our area. It provides fun fundraising activities that we can not only write a check for but participate in and it allows us to meet great families, that need assistance!” – Dean Pells

2021 Direct Mail Campaign & 2020 Annual Report cont.

Three years ago, Crystal Hoey began volunteering with SBANENY assisting with behind-the-scenes work for the office. Since then, she has joined 2 committees, contributes in-kind and monetary donations to SBANENY fundraisers, volunteers at community programs and events, and is joining the Board of Directors in 2022. Here is why Crystal gives to SBANENY:

1. *"To keep learning and educating others about the needs of individuals living with Spina Bifida*
2. *To advocate for inclusivity and access for individuals with Spina Bifida so that they can live, work and play in their communities*
3. *To advocate for necessary services educationally, medically and vocationally*
4. *I feel it is important to give my time and resources to important causes in my community*
5. *IT'S FUN!!!! It's fun participating in the events run by the organization. It's fun meeting new people. It's fun to plan, organize and participate in various programs and events. The SBANENY organization is a very friendly and welcoming group of people to work with!" – Crystal Hoey*



NOW WE KNOW WHY THESE SUPPORTERS GIVE, WILL YOU? >>> [GIVE TODAY!](#)

SPINA BIFIDA ASSOCIATION OF NORTHEASTERN NEW YORK 2020 ANNUAL REPORT



2020 Annual Report

The 2020 Annual Report is now available at www.sbaneny.org. In 2020, SBANENY...

- Advocated with U.S. Congress members and Senators at the national Spina Bifida Association's 3rd annual Teal on the Hill event
- Was included in the Aid to Localities Bill securing funding for programs and services through the NYS Department of Health for the first time in SBANENY's history
- Informed all known consumers when Albany Med established their first ever Adult Spina Bifida Clinic—only 1 out of 28 to exist in the country!
- Instituted remote internships
- Tripled the frequency of programs, expanded the reach of our programs across NYS and increased the number of consumers in attendance

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](#)

Virtual Adult Group

- Our Virtual Adult Group will be the fourth Tuesday of each month. Join us for our next meeting on 7/27 @ 5:30pm. To register for July's group click [HERE](#)

COVID-19

New York State: COVID Vaccine Incentives

- New York State is 70% vaccinated as of June. As the vaccine movement continues, NYS has started offering a variety of incentives to residents who get the shot
- Learn more about each vaccine incentives below:
 - [Free Two Day Pass to State Park of Choice](#)
 - [SUNY/CUNY Scholarship for Teens](#)
 - [Vax and Scratch Lottery](#)

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 agency 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

Sara Struwe, SBA CEO & President provided an op-ed on telehealth and managing your health

- The Hill's recent article covers telehealth: how to get the most out of your sessions, and still enjoy its convenience without compromising your health. Click [HERE](#) to read

EMPLOYMENT

Employment Opportunities at Center for Disability Services

- The Center for Disability Services is hiring for multiple positions with plenty of openings! Click [HERE](#) to explore open positions and apply online

SOCIAL SECURITY

The Social Security Star: June Edition

- The June Edition of The Social Security Star, the SSA's monthly newsletter is out! Topics covered in this month's issue include: SSA Benefits for Business Owners, Spouse Eligibility, Checking Your Benefits Online, and more. Click [HERE](#) for the English version, [HERE](#) for the Spanish version

SCHOLARSHIPS

2021 NCIL Youth Scholarship Applications Now Open!

- NCIL will be offering scholarships to individuals with disabilities ages 16-26 to cover the cost of attendance to their Annual Conference. Any conference attendee who identifies as BIPOC (Black, Indigenous, and/or Person of Color) can waive their registration fee by registering with the discount code BIPOC. BIPOC youth do not need to apply for a youth scholarship to have their registration fee waived. They may simply use BIPOC discount code on NCIL's online registration form. Click [HERE](#) to learn more about the scholarship and apply

SURVEYS

OPWDD Vaccine Accessibility Survey

- OPWDD wants to hear about your experiences getting vaccinated. This information will be used to address inequity in vaccine information and access. This survey is seeking information from parents of a child 12 years and up

Click [HERE](#) to complete the survey and learn more

LEADERSHIP OPPORTUNITIES

Self-Advocacy Association of NYS: Board of Election Process Has Begun!

- Are you are interested in becoming a nominee for SANYS Board of Election for the Capital Region, Upper Hudson Valley Region or the Lower Hudson Valley Region?
- If interested email: capitalhvelections@sanys.org
- The deadline to apply is July 31st

NEWS TO USE

ADAPTIVE PROGRAMS

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](#)
- Don't want to go to camp in person yet? Don't worry! Double H is still offering virtual ways to join in on the fun from home. Click [HERE](#) to learn more about the: Camp at HHome program

STRIDE: Adaptive Archery Workshops for the Month of July

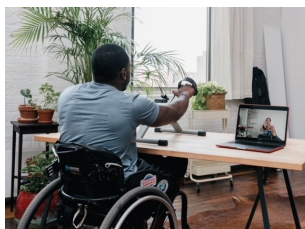
- STRIDE will be hosting adaptive archery workshops for the month of July! Workshops will take place on the 10th, 17th, and 24th from 10am –12pm at the STRIDE-SCORE camp (2166 NY-203, Chatham, NY 12037)
- Questions? Email Pat Hayslett, Development Director at phayslett@stride.org. Click [HERE](#) to see STRIDE's other upcoming programs this summer! Events include: art deco camp, top shop camp, kayaking, music and movement camp, and WW camping weekends!

Outdoor Accessibility Day!

- The Independent Living Center will be hosting an open house in the Adirondacks at John Dillion Park near Long Lake, NY
- Activities at the event include: pontoon boats, interpretive hikes, adaptive fishing clinic, camping demonstrations, and more
- Sunday, August 8th, from 11am—4pm
- Click [HERE](#) to register

Kakana: Virtual Adaptive Workout Classes

- Access Kakana from your home and the workouts are designed to be accessible first. Join our 7+ live adapted fitness classes a week or access our on-demand library at your convenience. Instructors with and without disabilities that have relatable life experiences allow Kakana instructors to teach and relate to each individual
- Click [HERE](#) to learn more and start your free trial



ADVOCACY

Self Advocacy Online Community HUB

- This FREE Online Hub provides you access to research, videos, local support groups, and other relevant resources. Content is tailored to each user, showing them the most appropriate information. Click [HERE](#) to access the HUB!

The Office for the Advocate for People With Disabilities

- The Office of the Advocate was originally established by Gov. Mario Cuomo and intended to represent the interests of people with disabilities in state government. The reconstituted Office of the Advocate will center the experiences of New Yorkers with disabilities and ensure their needs are considered when formulating policy
- July 2021 is the 31st anniversary of the ADA. Cuomo can champion the spirit of his father, the ideals of the Empire State and the voices of 1.1 million New Yorkers with disabilities by signing this bill in July. Reinstating the Office of the Advocate will be another example of how #NYLeads. Click [HERE](#) to learn more

Call To Action: Tell Congress to Pass the Better Care Better Jobs Act

- The ARC is calling attention to the Better Care Better Jobs Act, a bill that proposes a \$400 billion investment in Medicaid home and community-based services (HCBS) to expand access to these vital services and create more and better direct care jobs. Click [HERE](#) to take action and learn more

Americans With Disabilities Act Anniversary

- July 26th 2021 is the 31st anniversary of the passing of the Americans with Disabilities Act (ADA). Learn more and share the below links to raise awareness within your network:
 - [What is the ADA?](#)
 - [ADA Questions and Answers](#)
 - [Video: What is the ADA National Network?](#)
 - [Accessible Healthcare](#)
 - [ADA Research Brief: Health Care Access and the ADA.](#)
 - [Practical Recommendations for Enhancing the Care of Patients with Disability](#)
 - [Improving Access to Care for People with Disabilities](#)
 - [Improving Access to Telehealth.](#)
- Click [HERE](#) to watch SBANENY's ADA Video



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!

Adult Group

July 27, 2021

Mets Game

August 1, 2021

TRAID Information Session

August 5, 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— July 22, 2021

Development—August 11, 2021

Governance - August 3, 2021

Board of Directors— September 11, 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.