



SBANENY Newsletter

WELCOME LETTER

Happy New Year! Welcome 2021. My name is Jim Dunham and I have the honor of being the new Chair of the Board for this upcoming year. Last year was a challenge for almost everyone, and the Spina Bifida Association of Northeastern New York (SBANENY) faced these challenges by providing virtual events and programs. We plan to continue doing that as we begin this year, while hoping that we will also be able to provide in person activities by the end of the year.

Coming up this winter SBANENY is kicking off a 30-Day Wellness Challenge beginning on February 15th with virtual adaptive workout programs, nutrition classes, meditation and mindfulness programs, contests, incentives, prizes and raffles! Also coming up this winter is a new program, the Strut & Stroll: A Fashion Show for All. This virtual fashion show is for individuals 4+ to model adaptive clothing and footwear and participate in a roundtable with the designers. For more information keep reading this newsletter!

You can also save the date for SBANENY's annual events that are taking place virtually this spring. Mark your calendar! On April 17th we are hosting a Virtual Conference and on May 15th we will have our Virtual Walk-N-Roll. Follow us on Facebook or visit our website at www.sbaneny.org for additional details.

I would like to welcome and introduce to you our new SBANENY Board members. Andrew White and Valerie Joseph have just started their first term on our Board of Directors. Andrew lives in Richmond, VA, has three daughters, and enjoys playing the saxophone. Andrew comes to us as an author on books and articles and is involved in investment management. Looking to "give back" his long time friend Chip Derrick recommended SBANENY. Chip is also on our Board and beginning his second term. Valerie lives in Queens, NY and enjoys listening to music and event planning. She is a people person who is very familiar with the NYS Legislature where she advocates throughout the year on behalf of people with disabilities. She was recommended to us by her friend Joe Slaninka, another Board member who is currently serving his first term. Finally, we wish to welcome Shelley Miller back to our Board for another term! Shelley has chaired or co-chaired our Dare to Dream gala and Walk-N-Roll in the past.

If you are looking for ways to support SBANENY, please look further in this newsletter. There are many committees that could use your help and sponsorship opportunities for you and your business. If you'd like more information let us know! Thank you.

Board Chair
Jim Dunham

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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JANUARY 2021

WELCOME LETTER

DARE TO DREAM WITH
SBANENY

SBANENY PROGRAM
CALENDAR

SBANENY SUPPORTERS

EVENTS AND UPDATES

NEWS TO USE

COVID-19 VACCINE

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 Lukaszewicz
Jessica Ryder
Joe Slaninka
Andrew White

Executive Director
Julia Duff

Dare to Dream

90
families
attended

\$22,000
raised for
SBANENY

75
baskets
won

Watch the evening presentation here!

Congratulations to our Dare to Dream awardees!

- **Kim Hill, You Make a Difference Award**
- **Meghan Smith, SBANENY Volunteer of the Year**
- **Lyndsi Holmes-Wickert, National SBA Volunteer of the Year**

FEATURED PERFORMERS

**Madison
VanDenbrug,
American Idol
Finalist in 2019**

**Maddie Gallagher,
teen living with
Spina Bifida**

Thank you to the 2020 Dare to Dream Planning Committee!

- **Michelle Miller, Chair**
- **Abby Mundell**
- **Ann Humiston**
- **Jessica Ryder**
- **Judy Fillmore**
- **Karen Ballester**
- **Kevin Chamberlain**
- **Karen Wentworth**
- **Peg Smith**

SBANENY Calendar

SBANENY Legislative Days via Zoom!

◆ Monday February 8th, 9:30am-3:30pm.

◆ Additional dates: Tuesday 2/9, Monday 2/22 and Tuesday 2/23

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 and participating in the meetings scheduled to share your story, raise awareness, and make a difference.

Currently scheduled meetings:

February 8th: Assembly: Woerner, Gunther, McDonald, Fahy, Walsh, Santabarbara. Senate: Breslin, Tedisco, Jordan, Hinchey

February 9th: Assembly: Tague, Steck, Solages. Senate: Kaminsky

If you want to attend or cannot attend but would like to submit a letter, reach out to learn more!



30 Day Wellness Challenge! February 15—March 17

SBANENY & SBAGNE's brand new program will make it easier for you to set individuals goal for your health and achieve them!

- ◆ Sign up for free and receive a program T-Shirt
- ◆ Complete weekly checklists to gain points towards prizes including grocery store gift cards, fitness drinks, and protein bars
- ◆ Health and wellness resources
- ◆ Virtual programs on Zumba, Dance, Nutrition, Meditation & Mindfulness
- ◆ Reflect on Sundays and set weekly goals with other members
- ◆ Celebrate your new habits and growth at the end of week 4

Sign up here! <https://forms.gle/VsmzMQMe8fSksXpK8>



Virtual Fashion Show

March 25, 2020

SBANENY & SBAGNE are hosting a Virtual Fashion Show for individuals ages 4+ living with Spina Bifida. Individuals can apply to receive fashion items from known brands, submit a picture/video for the fashion show and participate in a roundtable discussion with the designers!

Applications are required to appropriately disperse the clothing: Click the link to apply: <https://forms.gle/r1zvbCtnSjRDUVit9>

What brands are participating? Currently, we have secured known brands including Bold Body, Runway of Dreams, Zappos, Billy Footwear, IZ Adaptive, Uniteable, Stride Rite, Slick Chicks, Patti and Ricky, and Juniper. Stay tuned as we continue to update our designer list!

SBANENY Events & Program Updates

2021 Virtual Conference

Empowerment through Knowledge: Living with Spina Bifida

When: April 17, 2021, 9:00am-4:00pm

Where: A device near you!

Cost: \$15.00

Sessions: Neurosurgery, Dr. Adamo, Urology, Dr. Rehfuss, Orthopedics, Dr. Mantica and Dr. Dutt, Mental Health

Registration will soon be available at www.sbaneny.org

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



2021 Walk-N-Roll for Spina Bifida

The 2021 Walk-N-Roll presented by The Daily Gazette is not taking place in-person, but remains a celebration of the Spina Bifida community!

On May 15, 2021 we will be holding our 11th Walk-N-Roll for Spina Bifida® virtually. Individuals living with Spina Bifida, and friends and families in the community can walk or roll in their home or neighborhood to raise awareness for Spina Bifida. The event is free and will continue to include contests, prizes and fundraising incentives! However this year - location is not a barrier!

Registration: Available at www.sbaneny.org on 2/1/2021



SBANENY Scholarships

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

NEW THIS YEAR!

The SBANENY Technology & Related Supports

Scholarship provides 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. The scholarship is intended to be used towards the cost of or for reimbursement of technology and related supports.

Applications for all scholarships are accepted on a rolling basis so they are first come first serve! Find the guidelines and applications at www.sbaneny.org!

SBANENY Employment Training Program

We are now accepting applications for another intern to participate in the program!

The SBANENY Employment Training Program aims to provide working age individuals with Spina Bifida the opportunity to gain meaningful work experience via internship to expand upon job skills and work-related experience, enhance awareness of personal values, skills, and needs to promote gaining meaningful employment.

*Virtual and in-person internships available

*Part time, paid internship

*Positions are not permanent

*This round aims to support an intern whose employment goals have been impacted by COVID-19, but it is not a requirement.

Visit sbaneny.org to apply and find additional details.

This program is brought to you in partnership with:



**Developmental
Disabilities
Planning Council**

Thank you to our Dare to Dream Sponsors!

Silver Sponsors



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THE **DAILY**
GAZETTE
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Assemblyman John T. McDonald III
Senator Neil Breslin

Crystal and John Hoey
Congressman Paul Tonko Chip Derrick



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Bridge Wine & Liquor, Price Chopper/Market
32, Rotary Club of Glenville, Saratoga Olive Oil,
ZM Photography

YOU CAN DARE TO DREAM WITH SBANENY!

- * Join the committee
- * Contribute an in-kind donation to our auction
- * Become a sponsor
- * Email admin@sbaneny.org or visit www.sbaneny.org for more information!

NEWS TO USE

Office for People with Developmental Disabilities (OPWDD) is seeking volunteers to review the Access to Services Guide and participate in a focus group! Parents or people with disabilities who recently used the Guide, OPWDD's Services System, or those who are not signed up for OPWDD services but considered it should contact Communications.Office@opwdd.ny.gov.

New York State Developmental Disabilities Planning Council (DDPC) is seeking feedback from people with disabilities (ages 14-28) for their 2022-2026 State Plan. This feedback will be used for planning future DDPC programming. **Complete the survey [HERE](#) by 2/1!**

SBA National Catheter Research Survey: Do you or a family member use catheters? SBA, Paralyzed Veterans of America, Christopher and Dana Reeve Foundation, United Spinal Association, and Duke University, are asking you to take part in a survey on urinary catheter use, insurance companies and health plans. Click [HERE](#) to access it!

Pelvic Health Initiative for Women with Disabilities: Baylor College hosted a series of webinars discussing the importance of pelvic health for women with disabilities. Topics covered include sexual health, bladder and bowel management, mobility impairments, and quality of care. Check out the webinars [HERE](#).

National Disability Institute (NDI) and its partners, understand the devastating impact COVID-19 has had and will continue to have on the financial and personal health of people with disabilities, those with chronic health conditions, as well as their families and communities. NDI, LifeCents and AFCPE offer valuable resources available to assist persons with disabilities through the current financial crisis created by the COVID-19 pandemic, while also building their financial resilience to bounce back and emerge more financially prepared. Click [HERE](#) to watch.

The New York ABLE Program: is a tax-advantaged savings program for individuals with disabilities and their families to save for their current or long-term needs while maintaining their ability to benefit from federal benefits programs such as SSI, SSDI and Medicaid. **Open a new ABLE account by January 31, 2021, have a balance of at least \$50 on February 28, 2021, and you'll receive a \$50 match to help jumpstart your savings.** See [official terms and conditions \(pdf\)](#) for details.

Learn About Decision-Making: The ARC's Center for Future Planning created free resources to help learn about decision-making options for people with IDD; understand the myths and limits of guardianship; learn how to make, review, and adjust a decision-making plan throughout a person's life to maximize their ability to make their own decisions Click [HERE](#) to access the ARC's resources. Contact the ARC's Center for Future Planning at futureplanning@thearc.org.

The Christopher and Dana Reeves Foundation have an incredible resource for when it's time to get a wheelchair. There are many things to consider and it can often be overwhelming. Learn from community members in the paralysis community on how to select & maintain the right wheelchair. Resources provided include: webinars, search tools, podcasts and personal quizzes. Click [HERE](#) to access the resources!

ALBANY MEDICAL CENTER SPINA BIFIDA CLINICS



PEDIATRIC & ADULT SPINA BIFIDA CLINICS

Designed to provide convenient medical care, providing the opportunity to see multiple specialists in one visit on the second Friday of each month.

Pediatric Spina Bifida Clinic

Department of Developmental Pediatrics
391 Myrtle Ave #3b, Albany, NY 12208
Contact: (518) 262-5401

Dr. Adamo, Neurosurgery, Medical Director

Specialists

Lisa Newman, PA	Dr. Kogan, Urology	Dr. Howe, Urology
Dr. Rehfuess, Urology	Karla Giramonti, FNP	Dr. Mantica, Orthopedics
Dr. Dutt, Orthopedics	Dr. Lostritto, PM &R	Dr. Fahl, Gastroenterology
Jennifer Meyerhoff, LMHC, Clinic Coordinator		

Adult Spina Bifida Clinic

Neurosurgery Department
47 New Scotland Ave, Albany, NY 12208
Contact: (518) 262-5088
Dr. Adamo, Neurosurgery, Clinic Director

Specialists

<u>Urology</u>	<u>Orthopedics</u>	<u>PM&R</u>
Dr. Kogan	Dr. Mantica	Dr. Lostritto
Dr. Rehfuess	Dr. Dutt	

COVID-19 Updates & Information

The COVID-19 Vaccine is available to select groups of eligible NYS residents. While SBANENY can not offer medical advice, we can connect you to resources and information about the vaccine. Please reach out to your primary care physician to see if the COVID-19 Vaccine is right for you. Read below for resources, protocols, CDC publications, and FAQ's.

National SBA COVID-19 Vaccine Update

- Read [SBA's publication about the COVID-19 Vaccine](#). This article covers topics such as: the long term effects of COVID-19, possible vaccine risk factors, and health/ safety wellness tips.

CV19 CheckUp

- Find out how likely you are to get or spread COVID-19, how severe it might be if you get sick, steps to reduce your risks, and ways to have your needs met during the pandemic. You will spend just 5-10 minutes answering questions and then immediately receive a custom report based on your life and habits. It is free, confidential and designed to help you be safer and healthier during the pandemic.

Eligibility Requirements

- NYS is distributing the vaccine in phases and we are currently in Phase 1b which includes: people over 65, public safety workers, pharmacists and pharmacy staff, teachers and educators, and some essential workers. To learn more about group 1b click [HERE](#).
- NYS has launched a new web portal to determine your eligibility. Click [HERE](#) to insert your information and find out if you meet the criteria.

Scheduling an Appointment

- If you are eligible and have gotten approval from your primary care physician to receive the COVID-19 vaccine, you can schedule an appointment online or by phone. Appointments are required and there is currently no walk in vaccine clinic in NYS.
- Click [HERE](#) to schedule or call [1-833-NYS-4VAX \(1-833-697-4829\)](tel:1-833-NYS-4VAX)

Albany Med Vaccine Portal

- Albany Med has created a COVID-19 vaccine portal to keep Capital Region Residents updated on the vaccine movement and its progress. Currently 30,000 residents have been vaccinated!
- Click [HERE](#) to access the portal

NYS Health Department: COVID-19 Q&A

- Do you still have questions about COVID-19, your rights, and state protocol? NYS Health Department has developed a web page with the most current publications and government acts. Information covered includes your rights under the Eviction Prevention Act, NYS micro-cluster strategy, and travel guidelines.

Emotional Support Hotline

- This pandemic has taken a toll on everyone, and we could all use some support. NYS has created a free, 24/7 mental health hotline to offer individuals support during these challenging and confusing times.
- Call [1-844-863-9314](tel:1-844-863-9314) for Free Mental Health Counseling and emotional support services.

COVID-19 Testing Information

- One of the most important parts of slowing the spread of COVID-19 is making sure we are testing regularly! If you were exposed to COVID-19 or are experiencing cold/flu like symptoms, contact your doctors.
- If you are in need of a COVID-19 test, and do not know where to go, you can use the NYS COVID-19 Testing portal to find a location near you. Click [HERE](#) to access the portal.

[RESOURCES—Visit the SBANENY website for a comprehensive list of COVID-19 resources!](#)

Ways to get involved with SBANENY in 2021!

SBANENY relies mainly on volunteers, donations and fundraising to provide programs and services for individuals and families living with Spina Bifida. You can make a difference by getting involved!

Join a committee!

All 2021 meetings are currently virtual. Consider joining a fun group of dedicated volunteers and SBANENY friends this year!

- ◆ Walk-N-Roll for Spina Bifida is seeking new members!
 - ◆ Virtual meetings 1x a month January—June
 - ◆ Assist with preparation of the event
- ◆ Dare to Dream with SBANENY
 - ◆ Virtual meetings 1x a month throughout the year
 - ◆ Assist with the planning of the gala and recruiting auction items
- ◆ Development Committee
 - ◆ Virtual meetings 6x a year
 - ◆ Assist with identifying and planning fundraising and development initiatives to support SBANENY's programming and services.



SBANENY Giving

NEW THIS YEAR! Visit www.sbaneny.org to...

- | | |
|---|---|
| <ul style="list-style-type: none">◆ Sign up to become a monthly donor◆ Use your SPARE change to make BIG change by signing up for SBANENY's Round up program◆ <u>Check out our 2021 Events Sponsor Guide with new support opportunities and company benefits!</u> | Other ways to give! <ul style="list-style-type: none">◆ Attend one of our annual fundraising events.◆ Celebrate your birthday with SBANENY on Facebook.◆ Recycle with SBANENY through Clynk.◆ Discuss matching gifts with your employer.◆ Host a 3rd Party Fundraiser. |
|---|---|

Volunteer

In-person and remote volunteer opportunities are available through SBANENY! This is a great way to learn about who we are and what we do! We often find our volunteers go on to join a committee or even the Board of Directors. For more information, email admin@sbaneny.org!

Welcome to our new members of SBANENY's Board of Directors in 2021!

Congratulations Michelle Miller, Valerie Joseph, Andy White. From all of us at SBANENY, we appreciate your willingness to share your personal and professional expertise and look forward to seeing what we can achieve together over the next three years!



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!

Sweat With SBANENY and SBAGNE

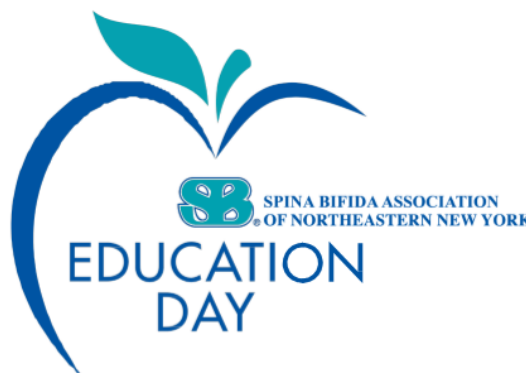
February 15, 2021

Strut and Stroll Fashion Show

March 25, 2021

Virtual Conference

April 17, 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— February 3, 2021

Walk-N-Roll— February 10, 2021

Fundraising and Marketing—March 6, 2021

Governance - February 11, 2021

Board of Directors— March 13, 2021

COMMITTEES TO JOIN

Conference

Dare to Dream

Walk-N-Roll

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.