Greetings and Happy New Year! 2019 promises to be an exciting year at SBANENY and I am excited to be sharing with you all what we have to look forward to.

First and foremost, I would like to congratulate Julia Duff for her new role as Executive Director. For the past 3 years Julia has been our case manager. During 2018 when the position of Executive Director opened up, Julia proudly applied. The search and transition committee worked diligently on finding the right Executive Director and when Julia interviewed, we knew she was the one. The SBANENY Board feels confident that Julia will steer us in the right direction in 2019 and for many years to come.

With the promotion of Julia, our office is shorthanded while the search and transition committee looks for new staff. In the meantime, we are seeking in-office support. If you or someone you know has time available to volunteer, contact the SBANENY office. Or, consider joining one of our volunteer committees. This year, we plan to reactivate our program planning committees and advocacy committee. Volunteer opportunities are flexible, so please let us know if you can become involved in any way!

2019 is offering some amazing opportunities to get together for networking, friendship and of course, loads of fun! Mark your calendars for...

Our annual advocacy efforts begin this month. Please consider joining us in Albany, NY during our legislative visits or, join us for National SBA’s Teal on the Hill in Washington D.C.. Our 9th Annual Walk-N-Roll for Spina Bifida & 2nd annual 5k at Central Park in Schenectady will take place again this year on May 18, 2019. Following in June is the SBANENY Car Show & Food Truck Event being held at Morris Ford. During the summer, we will return to Y-Knot sailing for young families and adults to learn about adaptive sailing on Lake George. Come Fall, we will again be supporting the Eric Crow Memorial Golf Tournament which donates funds raised to SBANENY. In October, we return to Double H Ranch for the fall family weekend retreat with families living with Spina Bifida in NYS and beyond. We end the year celebrating with our Dare to Dream gala. We hope you join us this year.

Finally, I am going to be the Chair of the Board this year. I previously served as Vice Chair and I’m looking forward to my new role. I have worked in advertising and fundraising for the past 30 years and I look forward to meeting you this coming year. I would like to invite you to get involved in the organization by attending programs and events, volunteering for one of our fundraising events such as Walk –N- Roll and Dare to Dream or perhaps if you have more time, serve on one of our committees such as Fundraising and Marketing, Board Development, and Policy and Procedures, to name a few. Together I know that we can achieve great things this year!

Thank you.

Tracy Paige, Board Chair

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Thank you to our 2018 Dare to Dream Sponsors!

★

TITANIUM
Socha Plaza
Daily Gazette

HONORARY COMMITTEE
First NY FCU
Dave & Karen Wentworth
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Jim & Eleanor Dunham
Codino’s Food

SILVER
Kevin & Vanessa Chamberlain
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DNA Signs

BRONZE
CBRE-Albany
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Media Well Done

“Congratulations to SBANENY on 25 years!”
- The Chamberlain Family

As the very proud father of an extraordinary daughter with Spina Bifida, I have watched her dare to dream. I have watched her live every day of her life with passion. I have watched her embrace the epic and enthralling adventure that is life. I have watched her soar...

Edward J. Johnson, Jr.,
InfoEd Global, President
NEWS TO USE

SCHOLARSHIPS AVAILABLE

Frank Bucino Jr. Memorial Scholarship

The purpose of this scholarship is to award financial assistance to individuals with Spina Bifida of any age living in NYS to support:

Conference Attendance: Individuals and their immediate family’s attendance at a national or regional Spina Bifida conference.

Educational Scholarship: Individuals with Spina Bifida who are pursuing higher education or technical training.

HELEN R. MERTENS EDUCATIONAL SCHOLARSHIP

The Helen R. Mertens Scholarship assists persons who have Spina Bifida living in Northeastern NY who are pursuing higher education, technical training, or driver’s education.

Find the applications at www.sbaneny.org

Applications are accepted on a rolling basis in 2019

ADDITIONAL SCHOLARSHIPS & FINANCIAL RESOURCES

National SBA: http://spinabifidaassociation.org/scholarships/
180 Medical: offers scholarships to students with Spina Bifida attending a two-year, four-year, or graduate school program. https://www.180medical.com/
ABC Medical: offers scholarships for adaptive sports, scholars and making a difference: http://www.abc-med.com/scholarships
American Association on Heath and Disability (AAHD): offers $1,000 scholarships to students with a disability who are pursuing undergraduate/graduate studies. https://www.aahd.us/initiatives/scholarship-program/
Gabriel’s Foundation of Hope: $500 scholarships and grants for people with disabilities. http://www.gabeshope.org/resources/scholarships/
J-Rob Foundation: offers grants for adaptive sporting equipment to children with physical disabilities or challenges, who are 18 years of age or younger. http://www.jrobfoundation.com
Jakes Help From Heaven: supports individuals with multiple medical challenges and disabilities. Applicants must live within 100 miles of Saratoga, NY. www.jakeshelpfromheaven.org/

Know of other financial resources that may help an individual and/or family living with Spina Bifida?

Have a financial need that is not addressed here?

Contact SBANENY to share or learn about other financial resources.

Housing Resources:

Habitat for Humanity of Schenectady Ramp Up program builds ramps to make entrances accessible for people with disabilities. Featured below, is Lyndsi Holmes-Wickert’s house with a ramp built by Habitat for Humanity. Lyndsi shared with us that residents of Schenectady County who are interested must complete an application, demonstrate proof of home ownership, insurance and income. The only associated cost is the building permit which depends on the town you live in. In Lyndsi’s case, she received a ramp for free during three months time. The time frame is subject to change depending on the time of year and organizations agenda.

If you are interested, call Lois at Habitat for Humanity: 518-395-3412.

Shady Lane Apartments. Located behind Socha Plaza in Glenville, NY, Shady Lanes has apartments that are or can be modified to meet accessibility needs. Are you looking for housing options? Call Shady Lanes: 518-399-0990.

Healthcare & Advocacy updates from the SBA:

On World Spina Bifida Day, the Spina Bifida Association shared the updated Guidelines for Spina Bifida Care. These guidelines involved over 100 medical experts and took three years to create. Find them now at spinabifidaassociation.org/guidelines/ and SHARE them with your healthcare provider!

Save the date: Teal on the Hill is taking place May 6-8, 2019 in Washington D.C. Participate in National Advocacy efforts withSBANENY. The cost of registration is $200; scholarships and online participation are available. Please contact SBANENY if you are considering attending this national advocacy effort!

Transportation Research

Share your thoughts on transportation needs in the disability community by participating in this survey from the Capital District Transportation Committee: https://www.surveymonkey.com/r/5YXZ299

Free Tax Prep

The Volunteer Income Tax Assistance (VITA) program offers free tax help to people with disabilities who need assistance in preparing their own tax returns. IRS-certified volunteers provide free basic income tax return preparation with electronic filing to qualified individuals. Visit this link to find a VITA location near you: https://www.irs.gov/individuals/free-tax-returnpreparation-for-you-by-volunteers
GET INVOLVED WITH SBANENY IN 2019

SBANENY provides information, referrals, support, education, advocacy, and programming for individuals and families living with Spina Bifida. As the only affiliate of the National SBA in New York State, we respond to calls for information and support from across New York State. With only one full time staff, we rely heavily on our generous volunteers. Consider joining in on the fun this year by participating on one of our committees:

Advocacy

Finance & Investment

Board Development

Policy & Procedures

Dare to Dream with SBANENY

Program Planning; Young

Fundraising & Marketing

Family & Adult

Walk-N-Roll & 5k

ADVOCACY: SBANENY Raises Awareness for Spina Bifida with Elected Representatives.

SBANENY is planning our annual advocacy efforts with staff, volunteers and consumers to attend a series of meetings with key New York State representatives from the Senate and Assembly. The purpose of the project is to raise awareness about Spina Bifida and the needs of this community, provide an update about SBANENY, its activities, needs, and concerns, and to identify actions that representatives can take to support the SBANENY mission. This activity also provides an opportunity to teach and practice advocacy to our youth, teens, and adults living with Spina Bifida. Participants have an opportunity to speak about their concerns related to Spina Bifida. They can address barriers in the community that challenges their ability to maximize their potential, as well as needs in the community that are critical to improving the quality of life for this community. Visits with the Governor’s office will be scheduled during the months of September and October. Are you interested in self-advocacy, peer advocacy, and systems advocacy?

- Consider joining our advocacy committee and participating in meetings
- Share a letter with your representative! SBANENY can help with the draft and finding your local representative
- Call your representative and share your Spina Bifida related needs
- Learn about the Spina Bifida Association's National advocacy efforts here: http://spinabifidaassociation.org/advocacy/

Consumer Advocacy Training: SBANENY recently attended a consumer advocacy training by Consumer Directed Personal Assistance Association of NYS (CDPAANYS), New York Association on Independent Living (NYAIL) and the Independent Living Center of the Hudson Valley (ILCHV). Speakers included Cliff Perez, MSW, Systems Advocate at the ILCHV and Brian O’Malley, Executive Director of CDPAANYS. See below for take-away information from the training!

- Advocacy requires you to do something. Therefore, an advocate is a person who takes a stand on a position or issue and then, takes action! Advocacy is used to promote an issue and influence and encourage change.
- There are five ways to advocate: Political (meeting with legislators), System/Administrative (meeting with bureaucrats and rule makers), Media/Education (contacting news and media outlets, letters and phone calls), Direct Action (taking the streets, using signs), Legal (filing a suit).
- Factors affecting advocacy efforts: money, votes, exposure in the media, and coalition building.

Tips:

- Tell your story… “This is what happens to me on a daily basis.” Emotion and storytelling are the most powerful advocacy strategies. Analytics are a strong supplement. Your representatives are here to support YOU in your community.
- Set the agenda and maintain focus on the priority for that meeting. A person may have a great story to tell but if it is not aligned with why they are there on that day, the message can get lost.
- There is power in numbers. When organizations and groups “divide and conquer” it poses less of a threat then if they address shared goals as a united front.
- Learn about who you are visiting. Knowing their interests adds a personal touch that makes the meeting memorable.

This Consumer Advocacy Training report is presented by Julia Duff, LMSW
2018 You Make a Difference Award winner, Dr. Barry Kogan, Chief of the Division of Urology at Albany Medical Center. Thank you to Dr. Kogan for over 20 years of dedication to the Capital Region Spina Bifida Community.

Thank you to our sponsors, donors, honorary committee persons and businesses, Board of Directors, Dare to Dream planning committee, and guests for making the night a success and contributing to the services provided by SBANENY!

HELP US SELECT OUR 2019 YOU MAKE A DIFFERENCE AWARD WINNER! Who do you think makes a difference for the Spina Bifida community? Contact the office and let us know!

Consider joining the fun and helping plan this event in 2019 by joining our committee!
Welcome
Chris Darby – King and Helen Eggenberger to our Board of Directors. Both Chris and Helen are founding parents of SBANENY. Thank you for continuing to support the growth, development and mission of SBANENY.

Congratulations Alexa Wyszmorski
Alexa was the first person hired through the SBANENY Internship Program; a training program to assist with the development of important workplace skills for young adults living with Spina Bifida. This Fall, Alexa officially transitioned to a part time employment position and is no longer an intern with SBANENY. We wish her the best in her future employment endeavors!

Summer & Fall Programs
Y-Knot Sailing: Youth & Adult options this July & August
Double H Ranch: October, 2019! Keep an eye out for official dates.

SAVE THE DATE! Saturday, May 18, 2019
SBANENY WALK-N-ROLL FOR SPINA BIFIDA & 5K
Captains! Get your teams ready. The online portal to register and raise funds will be available soon! Contact the office for offline forms.
Corporations! Contact SBANENY to schedule your corporate breakfast. SBANENY will visit your office, share information about Spina Bifida, SBANENY and starting a Walk-N-Roll team! This is a great way to get volunteer hours for your employees.
Sponsors! Contact SBANENY for a list of sponsor options and benefits. admin@sbaneny.org/518-399-9151.

SBANENY Giving
The 2017 Annual Report is now available at www.sbaneny.org. You will see in our financial report that SBANENY relies mainly on our major donors and fundraisers to provide support services. How can you help support SBANENY in providing services?
1. Purchase a newsletter advertisement.
2. Clynk by Hannaford: Donate your recyclables to SBANENY and we will drop them off for you. Or, pick up a recyclables bag & tag from the SBANENY office and drop it off at your local Hannaford. Funds from the recyclables are donated to SBANENY.
3. Amazon Smile: Select SBANENY as your charity of choice! Do your regular online shopping and have a portion donated to SBANENY at not cost to you.
4. Purchase an event sponsorship for you or your business. Sponsor benefits include media publicity (press releases, social media, newspaper and radio), logo placement on banners, t-shirts, our website and more! Dual sponsor opportunities and benefits for the Walk-N-Roll & Dare to Dream fundraisers are available today!
5. Celebrate your birthday with SBANENY on Facebook! Thank you to everyone who had shared your birthday with SBANENY in 2018!
6. Enroll in payroll giving through your employer.
7. Enroll in automatic monthly donations to SBANENY for the year.
8. Submit your donation to your employer’s matching gift program.
At this year’s Dare to Dream gala, the Spina Bifida Association of Northeastern New York celebrated our 25 year anniversary. Over 25 years ago, parents of children living with Spina Bifida and local community members conceptualized SBANENY and dedicated themselves to starting a not-for-profit organization to provide support for the individuals and families living with Spina Bifida. In 1993, the Spina Bifida Association of the Albany/Capital District became officially recognized as a not-for-profit. Over 15 years later, the organization began doing business as (DBA) the Spina Bifida Association of Northeastern New York, or as we like to call it “SBANENY.” Our service area was more accurately reflected with this change in name, demonstrating our reach went beyond the Capital District area. Since moving into Socha Plaza, our organization has been recognized as the Albany/Capital District chapter on our office signs. As of today, our signs officially show the name we have called ourselves for the past ten years. This would not be possible with DNA Signs. Thank you!

Thank you to our founders who dared to dream more than 25 years ago!

Not photographed:
Dana Berti and Paul Cassillo
Jeanette and Mike Bromirski
Ruth Kelleher
Cathy and Mark Wyszomirski
MaryBeth and Ken Burditt
Dan and Susan Stec
Titanium Sponsor

Hometown Hospitality | TheGlassTavern.com

SOCHA PLAZA
115 Saratoga Road | Glenville, NY | 518-399-0990 | Sochamanagement.com
“Best wishes to SBANENY as you Dare to Dream for the consumers that you serve!”

The Locally Owned Voice of the Capital Region for over 120 years

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OUR PURPOSE IS
Support
Health & Wellness
Awareness
Respect & Dignity
Empowerment

ABOUT SBANENY

UPCOMING EVENTS

WALK-N-ROLL FOR SPINA BIFIDA
& 5k
Saturday, May 18 2019
Central Park, Schenectady NY

Y-KNOT SAILING
July & August 2019

DOUBLE H RANCH
Fall Family Retreat
Lake Luzerne, NY
October, 2019

DARE TO DREAM
November, 2019
Wolfert’s Roost Country Club

COMMITTEE MEETINGS

Walk-N-Roll— 2/5/19
Dare to Dream— 2/12/19
Board of Directors— 3/9/19

COMMITTEES TO JOIN

Advocacy
Board Development
Dare to Dream
Fundraising & Marketing
Finance & Investment
Program Planning
Walk-N-Roll

FOR MORE INFO:
Email: admin@sbaneny.org
(518)399-9151
(518) 399-5639
Call us toll free: 855-722-6369

VISIT OUR WEBSITE —
FIND US ON FACEBOOK!
Website: sbaneny.org
facebook.com/sbaneny

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.

Become a sponsor, plan to attend, or donate at sbaneny.org.