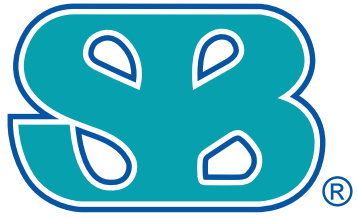


Fall 2018



SBAGNE

news

Celebrating the Season

SBAGNE celebrates the holidays in style in Massachusetts



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SBAGNE is a group of parents, adults and children with Spina Bifida and dedicated professionals working together to support and encourage families and individuals throughout the Greater New England area. It is our goal to enrich the lives of those affected by Spina Bifida through education, parental support, social networking, advocacy and public awareness.

Consider helping SBAGNE meet its goals with a personal or matching donation. Visit SBAGreaterNE.org today to contribute.

Upcoming Events

Annual Holiday Parties

Thank you to everyone who attended the Massachusetts Party on December 2nd! Taking photos with Santa, making crafts, and catching up with everyone was so much fun! We hope you join us for our next party in January!

You're invited to our annual Maine Holiday Party!
Sunday, January 20, 2019 from 11:30-3PM
Ramada Hotel (490 Pleasant Street, Lewiston, ME)

Celebrate the holiday season with lunch, crafts, Santa, and raffle prizes.

RSVP to llambert@sbagreaterne.org or [Eventbrite](https://www.eventbrite.com). with the number of people in your party, the ages of children (13 and under), and the name of the person in your party with Spina Bifida.

BLING and BEST

BLING/BEST Weekend 2019 is scheduled for March 1-3 at the Marriott Hotel in Newton, MA. This year, we will combine BLING and BEST so that we can offer a fuller experience for both girls and boys. Email Andrew Vacca at avacca@SBAGreaterNE.org with any questions or if you would like to volunteer.

BLING/BEST is a weekend away for teen and tweens living with SB filled with activities, sports, education, health conversations, social connections, and fun.



Join our Adult Group

Our Adult Group meets monthly for dinner. Come eat, chat, and enjoy company with other adult members of the Spina Bifida community. We will be at Wahlburgers at the Hingham Shipyard (January 11 at 6:30PM), and Double Chin HK Cafe in Boston (February 4 at 6:30PM). Contact Laura Lambert at llambert@SBAGreaterNE.org for more details or to RSVP for the events.

Join our Falmouth Road Race team

Each year, SBAGNE constituents, friends, and supporters participate in the annual Falmouth Road Race. We are hoping to assemble a fabulous team for 2019. Team spots will be open to previous team members from January 1-12 and remaining spots will open to new participants on January 13. To join the team, email Laura Lambert at llambert@sbagreaterne.org.

The Falmouth Road Race is a major fundraising avenue for SBAGNE and a great way for members of our community to connect and enjoy the summer heat! To learn about the Falmouth Road Race, visit <https://falmouthroadrace.com/>. The next race will take place on Sunday, January 18, 2019.

Winter Activities

We all naturally want to cozy up to a fire with a mug of hot chocolate on a cold winter day, but why not embrace the season by reveling in the freshly fallen snow that is sure to come soon. Many mountains around New England offer adaptive skiing.

Ski Mountains

<https://www.skinh.com/adaptive-programs>
<https://nedisabledsports.org/programs/winter-programs/>
<https://skivermont.com/skivt-blog/2015/01/07/adaptive-skiing-programs-at-vermont-resorts/>
<https://www.wachusett.com/Learning-Center/Specialty-Programs/Adaptive-Lessons.aspx>

SBAGNE Circle of Strength

When you make a donation of \$500 or more, your philanthropic giving plays a critical role in shaping the future of SBAGNE. By making a commitment at this level, you lead by example and support the Spina Bifida Community. Your gift of \$500 or more sustains and strengthens the work of SBAGNE.

Please join today.

Circle of Excellence

\$10,000- \$24,999

*Personalized Naming Opportunity

A unique, customized certificate recognizing your support

Invitation to be on SBAGNE Advisory Board

Name recognition on our Donor Wall

Name recognition on SBAGNE Annual Report

Subscription to SBAGNE Newsletter

Circle of Aspirations

\$ 5000- \$9999

A unique, customized certificate recognizing your support

Invitation to be on SBAGNE Advisory Board

Name recognition on our Donor Wall

Name recognition on SBAGNE Annual Report

Subscription to SBAGNE Newsletter

Circle of Opportunity

\$2500 – \$4999

Name recognition on SBAGNE Annual Report

Subscription to SBAGNE Newsletter

Window Decal

Circle of Possibility

\$ 1000- \$2499

Name recognition on SBAGNE Annual Report

Subscription to SBAGNE Newsletter

Window Decal

Circle of Promise

\$ 500-\$999

Name recognition on SBAGNE Annual Report

Subscription to SBAGNE Newsletter

SBAGNE Awareness Bracelet

*For more details in personalized naming opportunities, please contact **Andrew Vacca** at avacca@SBAGreaterNE.org or **888-479-1900**

SBAGNE

Letter from the Executive Director

When I woke up the other day, I couldn't believe what my eyes were seeing. I thought it was that I hadn't had a cup of coffee yet, but, sure enough, after a coffee, the calendar still said December. I remember as a kid that the years seemed to drag on, but as I age, the years seem to fly by. That has certainly been how this year has felt to me. When I look back at all the events and programs that we have done over the last 12 months, the new faces I've met, and the conversations we've had, it seems like a very good dream.

This year, we've seen growth in our Walk-N-Roll program relaunching in Maine, a higher than anticipated fundraising total from our wonderful Falmouth Road Race runners, and planning enhancements to the BLING and BEST programs. We couldn't have done any of these things without you! Your support in accomplishing these things is one reason why SBAGNE is one of the best associations around. I'm looking forward to an even better 2019 and hope to see you out at any one of our events in the coming months. I wish you a Happy Holiday Season and an even better 2019!

Andrew Vacca



SBAGNE

Community News

Local constituent wins regional pageant

SBAGNE constituent, Lila Blackington recently won the title of Miss Northern States Pre-Teen. She competed in the 10-13 age bracket for the Miss New England Coed Pageant in Connecticut on August 12th. She also won in the categories of Actress and Model.

In November, Lila headed to Orlando to compete at Nationals and hopes to show other youth that. "If you dream it, you can do it." During the competitions, Lila promoted #TuftsKidsToyDrive, a program she created two years ago, after a hospital stay. She decided to make other children's hospital experiences brighter by delivering toys, craft items, and books. This year, she delivered 615 items to kids through the program.

To learn more about #TuftsKidsToyDrive, visit their Facebook page, <https://www.facebook.com/LilasTuftsKidsToyDrive/>. To learn about Lila as the Miss Northern States Pre-Teen, 2018, visit the Facebook page, [MAC, Miss Northern States Pre-Teen 2018 - Lila Blackington](#).

Folic acid outreach

SBAGNE had a table at the annual Massachusetts Conference for Women on December 5-6 to raise awareness about Spina Bifida prevention through the regular intake of folic acid. The conference offers motivation, networking opportunities, and skills to women entrepreneurs.

Ways to support SBAGNE

Donate to our Annual Appeal



We are currently running our annual appeal. Please consider donating to SBAGNE as part of your annual giving. Donate at <https://sbagreaterne.org/get-involved/make-a-donation/>.


Shop with Amazon Smile

Don't forget to use Amazon Smile for your online shopping! By shopping Amazon Smile and by making SBAGNE your non-profit of choice, you can support SBAGNE while continuing to shop through the same Amazon you know and love. Find out more by visiting [Amazon Smile](#).

Find us on Social Media

We are present on Instagram and Twitter @SBAGreaterNE and on [Facebook](#) and [Pinterest](#)! To always get the latest information, photos, and updates follow us online.

Happy Holidays!

All of us at SBAGNE would like to wish you a happy holiday season! To celebrate, we invite you to participate in a little friendly competition. We have hidden a tiny Fall leaf somewhere in this newsletter. The first three people to find it will receive a prize! Email Laura Lambert at llambert@SBAGreaterNE.org with the location of the leaf to play. 

Apply to our Empowerment Program

You are invited to apply to our Empowerment Benefit Program. The benefit funds may be used for reimbursement for adaptive equipment, camp attendance, recreation and activities, adaptive sports and recreation equipment, urological supplies for individuals over the age of 3, durable medical equipment, and assistive technology. Currently, children and youth aged 18 and younger who are living with spina bifida are eligible to apply.

We are now paperless

We have officially gone paperless! We consider this to be a great opportunity for us to improve our impact on the environment and to streamline our communications with you, our constituents. If you are not already on our e-mailing list, please email Laura Lambert at llambert@SBAGreaterNE.org so that we can make sure you receive our next newsletter electronically.

Jean Driscoll Award Applications are open

SBAGNE is currently accepting applications for the 2018 Jean Driscoll Award. This \$1,000 award may be used for educational, developmental, or assistive programs or needs, and will be awarded to a SBAGNE constituent, age 14 or older, living with Spina Bifida who best demonstrates the character and determination of the scholarship's namesake.

To apply for this award or to find more information, visit www.SBAGreaterNE.org and click the heading, "Financial Services."

This award is named after Jean Driscoll, an accomplished athlete and world-renowned speaker, who was born with Spina Bifida and has used a wheelchair since her early teenage years. Driscoll is a Paralympian who won silver medals in both the 1992 and 1996 Summer Games. She is a world record holder in the 10,000 meter track event, 10k, and marathon races. She also won the Boston Marathon eight times and is the only person in Boston's 105-year history to achieve this record.

Share your experiences with the SBAGNE Community

In each of our newsletters, we include articles from outside sources that can offer valuable insight and information. However, we know that we have experts, like you, right here in our greater New England community. That's why we are inviting you to submit an article to SBAGNE to be included in one of our upcoming newsletters. You can write about anything from your experiences with accessible travel, involvement in adaptive sports, building friendships, relationships, and connections while living with Spina Bifida, caregiving, parenting, adulting, and so much more. As constituents living with Spina Bifida, as caregivers, as medical professionals, and as family members, you are experts in your experiences and we hope you will consider sharing your experience and expertise with the rest of our community.

To submit an article to our newsletter, email it as a word document to Laura Lambert at llambert@SBAGreaterNE.org. If your article has been selected for a newsletter, we will let you know via email before sending out the newsletter.

SBA Guidelines for the Care of People with Spina Bifida

During October Awareness Month, the national SBA released a set of guidelines for health-care professionals on the care of people with Spina Bifida. Since not all medical and health-care professionals have a deep knowledge of Spina Bifida, carrying these guidelines with you may help improve dialogue between you and your doctor. [Download the PDF](#).

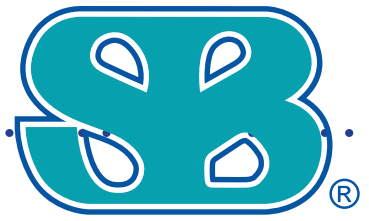
SBA National Updates

The national Spina Bifida Association has sent out the save the date for the next SBA advocacy event on Capitol Hill from May 13 - 15, 2019: TEAL ON THE HILL.

“Together, we can make our voices heard, advocating for policies to help ensure everyone with Spina Bifida has access to high quality, affordable health care. You have the power to make this happen and to educate lawmakers on the crucial issues affecting the lives of people with Spina Bifida.”

This event is open to all members of the Spina Bifida community. Registration is not open yet, but you can learn about TEAL ON THE HILL by visiting the national website here: <http://spinabifidaassociation.org/>.

In the News



Falmouth Road Race

We are so proud of SBAGNE's 2018 Falmouth Road Race team who raced on August 19th. Together, the team beat the fundraising goal of \$40,000 and the reach goal of \$55,000 to raise a grand total of \$62,881! We would like to express our appreciation for all of our amazing runners, especially our top fundraisers: Amy Wendell (\$18,475), the Packard Family (\$10,407), and Kim and Hannah Farrell (\$9,358). Congratulations to everyone for completing the race and thank you for your exceptional support of SBAGNE and our vibrant community!



Tour de South Shore

Thank you to everyone who participated in this year's annual Tour de South Shore on September 22nd! The team beat their goal to raise \$20,000 and raised \$33,461 for Spina Bifida! Thank you to the Holleran family for organizing the team and for supporting SBAGNE. The Tour de South Shore is an annual bike, walk, and run that takes place at Wompatuck State Park in Hingham, MA. It is hosted by The McCourt Foundation which serves people with neurological disorders and their families.

Maine Walk-N-Roll

Thank you to everyone who came to our Maine Walk-N-Roll on September 22nd at Capitol Park in Augusta, ME! Participants braved a windy day to walk and roll for Spina Bifida, picnic in the park, and party with DJ, Cody Bertrand.

**SOUTH
SHORE**

BIKE | RUN | WALK

**FOR NEUROLOGIC
DISEASES**

**WALK-N-
ROLL**
FOR **SB**

Spina-Beautiful Stories

Q: What is your name?

A: Amie

Q: What type of Spina Bifida do you have?

A: Myelomeningocele (L4/L5)

Q: How can we continue to follow your story?

A: @Amiejillian on IG

Hi! My name is Amie and I was born in 1989 to my parents, Janet and Al, who were completely surprised by the diagnosis. As my doctors explained it, I was born with "my nerves spilling out like spaghetti" and my doctors whisked me away without giving them a chance to hold me for quite a while. After a trip from Malden, MA to Boston Children's Hospital via ambulance, I had my first surgery (spinal closure) at 11 hours old, resulting in a scar that I "affectionately" call my crater. About two years and two more surgeries later, I was fitted with my first pair of AFOs, leg braces, and took my very first independent steps. Approximately 3 years after that (as a kindergartener), I had my first of 4 bladder-related surgeries. Overall, in my 29 years, I've had 9 Spina Bifida-related operations, my tonsils removed, and wisdom teeth extracted. While this number makes me feel like a hospital frequent-flyer, I know that I'm lucky and that others have had FAR more. I was lucky enough to not need a shunt at birth or later in life, and other health issues haven't crept up yet. It's an interesting feeling, though, to be so young and feel as though I've lived through so much. As individuals with a disability, we learn to adapt and "power through" the tough times with what we've been given and we really know no other way. And I'm not sure if I'd change that. (But ask me another day and maybe I'll have a straight answer for you.)

I was raised not to let Spina Bifida take away from my life. I played town soccer, learned to water ski at 12, swam a lot (and still would if I had the time!), went away to college (Keen State - NH), got my Master's Degree (Reading Specialty), worked my way to a great job that I love, got married, bought a house, and hope to have a family. I owe all of these things to hard work and determination, but also to the friends and family surrounding me who never treated me as "different." I'm just Amie . . . but I happen to have Spina Bifida. Even just being able to come to that conclusion took hard work. Accepting this side of me takes constant work. I often viewed my life as having two parts: the "normal" (hate that word) part and the Spina Bifida part. Meshing the two together is a goal I feel that I'm finally close to achieving. One way I'm working toward that is becoming more involved with the Spina Bifida community. I've had some opportunities to share my story locally and across the country and I'm now going to serve on Advisory Boards for the National Spina Bifida Association (with Kristin!). My hope is to continue this involvement, which includes attending Teal on the Hill in 2019 to advocate for the community in Washington D.C. Platforms like this one are close to my heart because they allow those affected by SB to come together and connect.



This article is reprinted from the blog Living Spina-Beautiful. The blog, written and monitored by Kristin Marquis, is built around empowering people living with Spina Bifida. Read about Kristin below.

I was born with Spina Bifida and it was a BIG surprise to my parents! My mother had a perfectly healthy pregnancy with no warnings. I'm sure you can imagine their surprise when the doctors whisked me away as soon as I entered the world! It must be a lot like thinking you're landing on a tropical island for the best vacation of your life and then the plane lands and you see volcanos, it's freezing cold; total chaos. Well, good luck...you have to stay and make do.

I'm still navigating life with Spina Bifida and it certainly has it's ups and downs. I believe I wouldn't be deal something I can't handle, and this just makes me a stronger woman...It makes me Spina-Beautiful!

To check out her blog go to <https://spina-beautiful.com>.

Join our Board of Directors

As we enter a new calendar year, our Board of Directors also begins a new cycle. Our board is made up of active community members who support and help plan community events, engage in fundraisers, and promote outreach and communication inside and outside the Spina Bifida community.

Meetings occur quarterly, with occasional conference calls and committee meetings. Committees are open to board members and volunteers. We hope you will consider joining our Board of Directors or volunteering on one of our committees. You can apply or seek more information by emailing Laura Lambert at llambert@sbagreaterne.org or Andrew Vacca at avacca@sbagreaterne.org.

Accessible Parties

This is one of the busiest times of the year, filled with holiday parties, family dinners, and vacations with loved ones., but we know that not all parties are made alike. Below, we've included links to a few blogs about making holidays more accessible for everyone.

<https://www.nmeda.com/accessible-holiday-gathering/>

<https://everydayfeminism.com/2016/02/how-to-make-party-accessible/>

<https://www.movementadvisor.com/disability-friendly-winter-vacations/>

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Note: The information in this newsletter is provided solely for informational purposes. It is not intended to be, nor is it, medical advice on the management or care of a person with spina bifida. Although every effort is made to assure that information is accurate and current, knowledge in the field of spina bifida is growing rapidly and all data are subject to change without notice. Neither the SBA of Greater New England nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The SBAGNE does not endorse any specific medical regimen. You should not change your medical schedule or activities based on the information provided in this publication. Always consult with a doctor, health care provider, or other medical professional before making any medical decisions. The SBAGNE does not employ medical personnel in its organization.



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