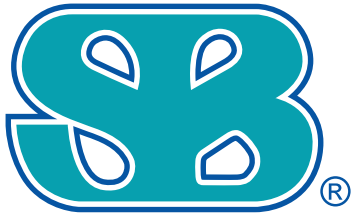


Winter 2017



# SBAGNE

*news*



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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](http://SBAGreaterNE.org) today to contribute.

## Upcoming Events

### 2017 Walk N Roll Announced! June 3rd

Way to go, **Emily Gagnon**! In 2016, Emily was recognized as one of the top three Walk-N-Roll fundraising individuals nationwide. Coming in second place nationally, Emily raised \$6,500. Altogether, chapters of the Spina Bifida Association held 24 walks, with 7,000 participants raising more than \$650,000.

**SBAGNE's annual Walk-N-Roll will take place this year on June 3rd.** Visit [SBAGreaterNE.org](http://SBAGreaterNE.org) for additional information, updates and to register today!



### Falmouth Road Race - Support Team SBAGNE August 20th

Join TEAM SBAGNE for the 45th running of the Falmouth Road Race  
**Sunday - August 20, 2017**



SBAGNE is once again fortunate to receive 25 entries for the Numbers for Non-Profits Program through the Falmouth Road Race. Team SBAGNE participants raise funds and awareness for SBA of Greater New England. In 2017 we hope to raise \$45,000.

Minimum fundraising amount is \$1000.

There are currently 13 runners registered to support SBAGNE.

If you are interested, or know someone who is – contact Laura at [llambert@SBAGreaterNE.org](mailto:llambert@SBAGreaterNE.org).

7 miles to support a fantastic cause, put your running shoes on, start training now!

### SBAGNE Adult Scavenger Hunt

Save the date for our first Adult Group Scavenger Hunt! The hunt is expected to take place on the afternoon of **May 6th** at the **Commonwealth Museum in Boston**. Exact time and arrangements are to be determined. Watch the [SBAGreaterNE.org](http://SBAGreaterNE.org) for updated information.

# Letter from the Executive Director

A belated Happy New Year to all. We hope the 2017 is a happy and healthy one for all. Planning is well underway for a busy and productive year.

In December, SBAGNE hosted 2 holiday parties, Augusta, Maine and Newton, Mass. Music, good food, friends and a visit from Santa – a great way to begin the holiday season. Plans for the upcoming months include: **Walk-N-Roll**, **Annual BLIN’G**, and a **Scavenger Hunt** for adults. Watch upcoming e-newsletters and [SBAGreaterNE.org](http://SBAGreaterNE.org) for additional information.

The **8th Annual Walk-N-Roll for Spina Bifida** will be held in **June 3rd** – time to begin your fundraising! Looking for ideas – SBAGNE has a DIY Fundraising Guide available on our website. A new incentive this year the opportunity to try and hit Rebecca Sherlock or myself with a whipped cream pie.

A final note, after almost 12 years, I will be leaving SBAGNE later this year. SBAGNE has experienced significant growth in service area and expansion of services and I am very grateful to have played a role in reaching ever greater numbers of the Spina Bifida community. I am appreciative of the support provided, knowledge gained, friends made and patience granted during my tenure. I look forward to the upcoming months and going out with a whipped cream pie in the face!

Best

*Ellen*

# Support SBAGNE with your Time



Do you, a family member or friend have experience in finance, marketing or development? SBAGNE is currently recruiting Board Members with skills in these areas. Committees are vital to maintaining the strength and efficiency of SBAGNE. If you have an area of expertise or interest that would benefit SBAGNE, **WE NEED YOU!** Committees typically meet monthly, via conference call. Calls are generally planned for a time in the evening and are approximately an hour in length.

**Internal Affairs:** Focus on finances and human resources

**External Affairs:** Focus on marketing, public relations and development

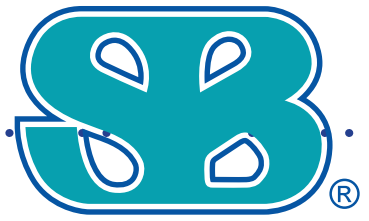
**Governance:** Health and functioning of the Board of Directors

Contact Ellen at [edugan@SBAGreaterNE.org](mailto:edugan@SBAGreaterNE.org) if you are interested or would like more information.

## Financial Resources

SBAGNE has developed a list of resources that may be able to assist in covering the costs of items associated with Spina Bifida. The list includes organizations that assist with medical costs, adaptive sports and other expenses. Also included is a list of organizations that provide various experiences i.e.: concerts, make a wish. This list is not exhaustive and we will be continuing to update. If you are aware of an organization that should be included – please email Ellen at [edugan@SBAGreaterNE.org](mailto:edugan@SBAGreaterNE.org).

# In the News



## Executive Director Search

SBAGNE is commencing a search for the next Executive Director.

Ellen has announced her retirement for mid-2017 and the SBAGNE Board of Directors has begun the search for the new Executive Director. Education and experience requirements include:

- Degree in an area relevant to SBAGNE's mission
- Working knowledge of people with disabilities
- Leadership or executive experience with a nonprofit organization
- Fundraising/development skills
- Management skills
- Public affairs/public speaking experience
- Passion for working with mission-driven organizations
- Innovative and entrepreneurial self-starter
- Excellent communication and consensus-building skills

The complete posting is available at [SBAGreaterNE.org](http://SBAGreaterNE.org) or by contacting Laura at [llambert@SBAGreaterNE.org](mailto:llambert@SBAGreaterNE.org)

**Application Deadline is March 15, 2017**

## Thank you

The SBAGNE Board of Directors and staff would like to thank **Dr. Stuart Bauer** for his years of service to the organization. Dr. Bauer has served on the Board for more than a decade, bringing insight, experience and most importantly, his commitment to those living with Spina Bifida.

We are grateful for his collaborative approach, humor and vision. Dr. Bauer will continue as Board Member Emeritus.



## The Ralph Braun Foundation

The Ralph Braun Foundation works nationally to provide vehicle modification grants to individuals with disabilities in need of financial assistance. Our mobility assistance grant program is designed to bridge the funding gap that prevents people in need of mobility products from achieving their mobility goals. We do this by offering grants of up to \$5,000 to people throughout the United States and Canada who have secured the majority of the funds needed, but require the final amount to complete their purchase. Our founder, Ralph Braun, believed that everyone has the right to accessible transportation and that is why he created this foundation: to help people achieve their dreams of mobility.

For more information, visit the [Ralph Braun Foundation Grant Program](#) page.

# Annual Empowerment Program

SBAGNE has been awarded a grant from Dunkin Donuts/Baskin Robbins Community foundation in support of the SBAGNE Empowerment Program. This benefit is for children ages birth to age 18. Payments must be made directly to a provider. For more information or with any questions contact [edugan@SBAGreaterNE.org](mailto:edugan@SBAGreaterNE.org). Applications can be downloaded at [www.SBAGreaterNE.org](http://www.SBAGreaterNE.org).

## Life Hacks

Have you ever stuck a phone or iPod into a empty toilet paper roll to amplify the sound? Or maybe you've used duct tape to open a jam jar? If you have done either of these things (or a slew of other tricks) then you've made use of a life hack. If you've never heard the term before, a life hack is just like how it sounds. It is an adaptation, which typically involves creating a new use for an old tool.

One of our favorite hacks is to construct a beach wheelchair out of PVC pipes and Balloon Wheels. This chair is one of the best ways to roll on the beach and, because it's homemade, is highly customizable! Watch for this and other Life Hacks soon!

## The Accessible Icon Project

The Accessible Icon Project is an ongoing work of design activism. It starts with a graphic icon, free for use in the public domain, and continues its work as a collaboration among people with disabilities and their allies toward a more accessible world. Visit [accessibleicon.org](http://accessibleicon.org) to learn more.



**SBAGNE relies on generous individual contributions to provide programs and services. Join the Circle of Strength today**

When you make a donation of \$500 or more, your philanthropic giving plays a critical role in shaping the future of SBAGNE. By a 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  
Circle of Aspirations - \$5000 - \$9999  
Circle of Opportunity - \$2500 - \$4999  
Circle of Possibility - \$1000 - \$2499  
Circle of Promise - \$500 - \$999

For more details in personalized naming opportunities, please contact Ellen Heffernan at [edugan@SBAGreaterNE.org](mailto:edugan@SBAGreaterNE.org) or 888.479.1900.

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You shop. Amazon gives.

Did you know that we have an Amazon Smile account? That means that you could be supporting SBAGNE every time you shop on Amazon without any added cost to you. Amazon will donate a portion of your purchase to SBAGNE without changing price or selection. This is a hassle-free way to continue supporting the Spina Bifida community. Just go to: <https://smile.amazon.com/ch/23-7305430>  
We also have a click-to option on our website page.

# It's the most wonderful time of the year!

Recently, SBAGNE hosted two delightfully festive holiday parties, one in Maine and one in Massachusetts. Both events were well attended and filled with holiday cheer. Attendees enjoyed tasty breakfasts, arts and crafts, silly Yankee swap gifts, and a friendly visit by a certain bearded, red and white garbed gentleman from the North Pole.

The annual holiday parties are a great way to build community and to create lasting connections. One first-time attendee, the mother of a 14 month-old girl, stated, "This was our first holiday party and we met amazing people. We honestly felt like we belong for the first time... as my daughter gets older she will have a place where she will fit, not be made fun of or feel different."

We would like to extend a very special thank you to all of our volunteers who helped make the parties a success! Thank you Maggie, Megan, Lena, and Jamie, who helped with the party in Massachusetts, and Emily, Kerri, and Heidi who helped with the party in Maine, for your big smiles and fun-loving attitudes.



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### Vice Chair

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### Treasurer

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### Clerk

Jason Paynich

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Dr. Stuart Bauer, *Emeritus*

Amy Bois

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Executive Director

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Operations Associate

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**Elizabeth Brodeur** (888) 479-1900

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### **Falmouth Road Race**

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### **Fund raising**

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### **Membership**

Ellen Heffernan-Dugan, Executive Director

Email: [edugan@SBAGreaterNE.org](mailto:edugan@SBAGreaterNE.org)

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Milford, MA 01757

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### **Walk-n-Roll**

Ellen Heffernan-Dugan, Executive Director

Email: [llambert@SBAGreaterNE.org](mailto:llambert@SBAGreaterNE.org)

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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