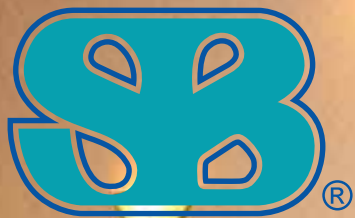


Spring 2015



# SBAGNE

*news*



### Summer Events

Focus on education,  
advocacy and FUN!

### Walk N Rolls

Get ready to Walk  
and Roll at one of  
four locations in 2015

### New Operation Associate

Jeff Vendetti

## CONTENTS

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## WALK-N-ROLL 2015

Planning is underway for the 2015 Walks. Begin to recruit team members and start your fundraising. The Walk-N-Roll is our largest fundraiser of the year. We need your support to reach our goals so we can continue programs and services.

This year we have four sites around the greater New England area:

**Massachusetts Hospital School**, Canton, MA - June 6th

**Rock Church**, Scarborough, ME - June 20th

**North Hampton**, MA, **Look Park** - September 12th

**Nashua**, NH - October 3rd (site to be determined)

Visit [SBAGreaterNE.org](http://SBAGreaterNE.org) for links to each site.

## Summer Picnic

**Mass. Hospital School, Canton, MA**

**July 18th, 10:30 AM - 3 PM**

SBAGNE is once again throwing its Annual Summer Picnic! Swimming, wheelchair-accessible pontoon boats, food and beverages and tanning are all yours for the taking! Come enjoy the company of other SBAGNE members and enjoy a fun day. For more information, directions and registration information, visit the [Summer Picnic Announcement](#).

## Fisher Cats Baseball

Join SBAGNE for an afternoon of good old-fashioned fun at a Fisher Cats game, Sunday, August 2, 2015 at the Northeast Delta Dental Stadium in Manchester, NH. For more information, [download the flyer](#) on the SBAGNE website under Events. Tickets are limited!

## Regional Education Days

SBAGNE is planning 3 regional education days in 2015. Tentative plans include events in Eastern and Western Massachusetts and Maine. Check upcoming newsletters for dates, locations and topics. These regional events will replace the larger Annual Conference. SBAGNE expects that by dispersing the events across our service area, we will reach greater numbers of individuals in the Spina Bifida Community.

## Falmouth Road Race

SBAGNE has once again been awarded 25 charity entries for the 2015 Falmouth Road Race. The race is on August 16th. If you are interested in participating as a member of TEAM SBAGNE, contact Jeff Vendetti for more information or visit the [SBAGNE FRR site](#) today. Minimum fundraising requirement is \$750.



## Hello All!

Finally we have warm weather coming in and no more SNOW! We have great events planned and hope you all can participate.

First I would like to welcome **Aimee Williamson** to our Board. She comes with great experience and knowledge of the non-profit world and we know she will be an asset to our organization. Welcome Aimee!

SBAGNE has four **Walk-N-Rolls** scheduled this year, taking place in Canton and Northampton Massachusetts, Scarborough, Maine and Nashua, New Hampshire. Please check out the scheduled dates and join in the event in your area. Remember that your donations make all that we do for you throughout the year possible so form a team or make a pledge today!

Once again **TEAM SBAGNE** is running the **Falmouth Road Race!** We are lucky to be a part of such a prestigious race. We have returning supporters as well as new participants running and raising funds. But ***we need more runners!*** If you or someone you know would be interested in running for we still have several numbers left. Please contact us for more information.

As always there are wonderful events scheduled for the spring and summer which you will want to attend. I encourage you all to go to our website to get the up to date information but do want to mention a couple of them to you: There will be a **Sailing Day at Piers Park in East Boston on Saturday, May 30th** that have boats that are able to accommodate manual and power chairs and a great park is there to have a picnic lunch and just enjoy the scenery! In addition there is going to be a **Hiking Day with Waypoint Adventures on Saturday, June 27th in Canton.**

Once again I would like to thank everyone who volunteers their time to assist with these events and make all of this happen.

Sincerely,

*Barbara*

Barbara Lee, Chair SBAGNE



## Register Now!

Log onto [SBAGreaterNE.org](http://SBAGreaterNE.org) and register for the Walk-N-Roll closest to you. SBAGNE is holding 2 walks this Spring, Canton, Mass and Scarborough, ME.

The walks are SBAGNE largest fundraiser of the year and tremendous community building events. Raise funds to support SBAGNE programs and services, connect with old friends and meet some new friends.

Come and join us on what we hope will be two beautiful sunny Saturdays in June.

The walks in Western Mass and Nashua NH are planned for the Fall. Register your team and begin fundraising now!



## Check out the SBA YouTube Channel!

<https://www.youtube.com/user/SBAOrg>

# In the News



## Welcome Jeff Vendetti!

### SBAGNE Operations Associate

Jeff Vendetti has lived in Franklin, MA for most of his life. During his childhood he lived in Foxboro, Franklin, and Naples, Florida, before moving back up to Franklin, MA nearly 11 years ago. Jeff has also recently graduated from Dean College with his Bachelor's degree in Business Administration and is currently earning a certificate in Business Analytics from Bryant University. He'll be starting his MBA in International Business there in the Fall as well. As of March 2015, he began working at SBAGNE as the Operations Associate. Although his time at SBAGNE has been brief, he is eager and excited to help out the organization and try to have a big impact.



## Mark Your Calendars!

*Spring is here and Summer is on it's way!*

Join SBAGNE for a series of events through the Spring and Summer. For more information, visit [SBAGreaterNE.org](http://SBAGreaterNE.org).

**May 30th - Sailing at Piers Park** East Boston. Youth and families 10 AM-1 PM, Adults 18+, 1 PM-4 PM

**June 27th - Hiking with Waypoint Adventures**  
Location Blue Hills, Canton, MA. All ages are welcome!

**October 17th - Rock Climbing**

Location: Quincy Quarries, Quincy, MA

## Annual Benefits Program

SBAGNE recently received a generous grant from the **Ramlose Foundation**. This grant will allow SBAGNE to reinstitute the Annual Benefit Program in a limited way beginning in July. Additional information regarding items covered and the application process will be available in upcoming newsletters and online.

A heartfelt thank you to the Ramlose Foundation!

## Adult Urology and Neurology Medical Providers

SBAGNE representatives, physicians from Boston Children's and Brigham and Women's have been meeting throughout the winter to discuss the need for transition to adult providers for members of the Spina Bifida Community. Future plans include the addition of other specialties, tours of the B/W facility and an opportunity to meet providers and a "Lunch and Learn" for adults to include presentations by adult providers. Watch your email and visit [SBAGreaterNE.org](http://SBAGreaterNE.org) for further information.

Brigham and Women's physicians are currently seeing individuals with Spina Bifida.

Dr Jairam Eswara, Urology  
Brigham and Women's Hospital  
Phone (617) 732-5627

Dr Mark Johnson, Neurology  
Brigham and Women's Hospital  
(617) 525-8135

# Giving



SBAGNE has initiated the **Circle of Strength** to recognize significant support from individuals, families and corporations. When you make a donation of \$500 or more, your philanthropic givings 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. visit [SBAGreaterNE.org](https://www.sbagreaterne.org) for more information regarding giving levels. *Please join today.*

## Annual Reports

Each year SBAGNE publishes it's Annual Report. You may download the latest and past reports by visiting: [SBAGreaterNE.org/about/annual-reports/](https://www.sbagreaterne.org/about/annual-reports/)



SBAGNE is conducting a series of surveys for Adults, Children and Professionals. Visit [SBAGreaterNE.org](https://www.sbagreaterne.org) or click on the links below to take the surveys.

Adults with Spina Bifida

<https://www.surveymonkey.com/s/NQKYQBQ>

Survey of Children with Spina Bifida

<https://www.surveymonkey.com/s/NQVWPJY>

Professional Survey

<https://www.surveymonkey.com/s/9PHTN87>

## SPEAK (Spina Bifida Policy, Education, Advocacy, and Knowledge)

Grassroots advocacy is at the heart of our advocacy efforts. Through grassroots efforts, our Community is empowered to take real action that can make a tangible difference for everyone who lives with the challenges of Spina Bifida.

To help grow these efforts, SBA has established the SPEAK for Spina Bifida program. SPEAK stands for Spina Bifida Policy, Education, Advocacy, and Knowledge. Participants in this program help to shape public policy and programs around Spina Bifida by interacting with their federal and state representatives in a variety of ways.

Visit [www.sbaa.org](https://www.sbaa.org) for more information.





The 5th annual BLIN'G (Better Living N' Girls) Weekend was held March 6th through 8th at the Newton Marriott. It was the largest group yet, 20 girls each with a parent! The weekend presentations included Chi Gong, healthy living, nutrition, staying active and mentoring. Once again the girls enjoyed the Saturday night pool party, movie and chocolate fountain! The weekend finished with makeovers and a lunch at Margarita's Mexican Restaurant in Waltham. Plans are underway for 2016!!!



# Contacts

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Operations Associate

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### Membership

Ellen Heffernan-Dugan, Executive Director

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Cara Packard

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### Walk-n-Roll

Ellen Heffernan-Dugan, Executive Director

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