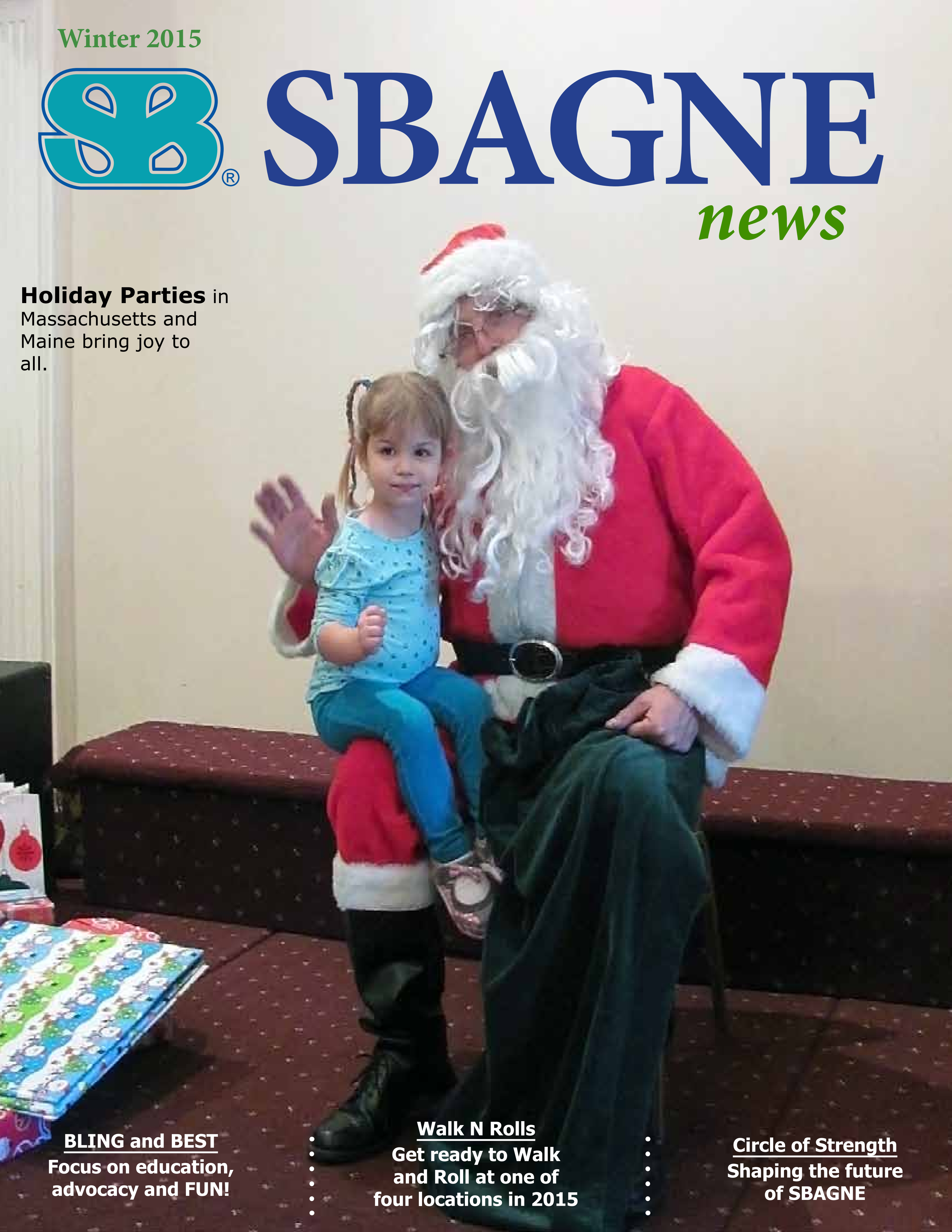
Winter 2015

SBAGNE *news*



Holiday Parties in Massachusetts and Maine bring joy to all.

BLING and BEST

Focus on education, advocacy and FUN!

Walk N Rolls

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

Circle of Strength

Shaping the future of SBAGNE

CONTENTS

Events

BLIN’G and BEST

BLIN’g and BEST are weekend-long events for tweens and teens and a parent ages 12-17. Focus is on education, advocacy an FUN! BLIN’G is being held March 6-8th at the Newton Marriott and BEST APRIL 24-26th in Canton, MA. For more information or to register, contact Ellen at edugan@SBAGreaterNE.org

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 out 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
Nashua, NH - October 3rd (site to be determined)
Western MA - September/October (site to be determined)

Visit **SBAGreaterNE.org** for links to each site.

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 Ellen for more information. Minimum fundraising requiement is $750.

Dear Members and Friends:

Happy New Year! A little belated but we are well into a snowy 2015! Hopefully everyone is ready for a brand new year with a lot to work towards and work on.

As we have communicated SBAGNE is actively working on development efforts for the organization. Of course this includes the events that everyone can look forward to.

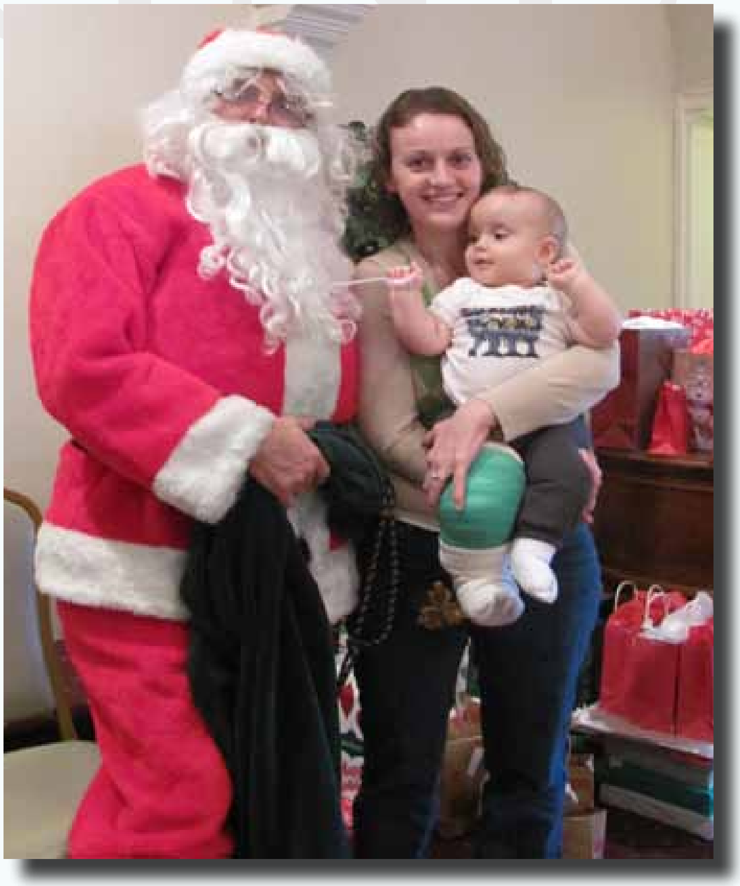
March for the 4 years, brings BLIN'G for young women and April brings BEST for our young men. Friday, March 6th will be upon us quickly and the young ladies can enjoy another jammed packed weekend with friends. BEST on April 24th-26th proves to be the same for our young men; plans for both events are well underway!

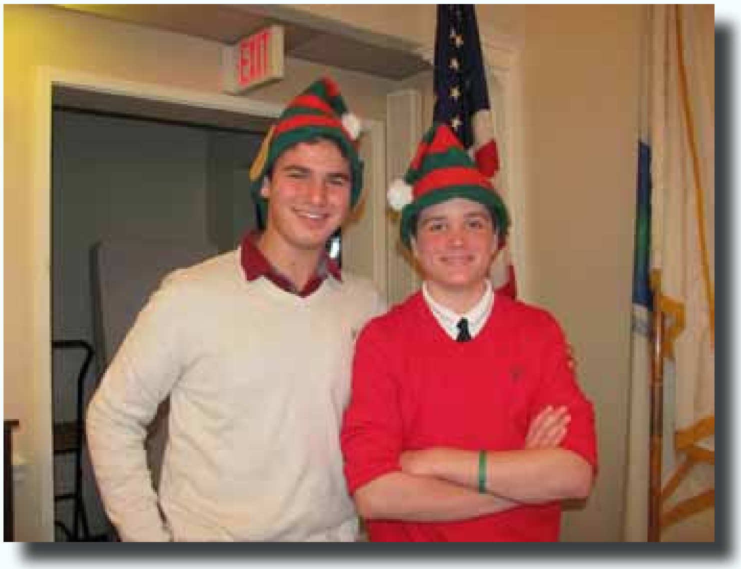
MARK YOUR CALENDARS - Walk n' Rolls dates are listed later in this newsletter. As always we are anticipating great participation and contributions from your family and friends. Your continued support for these events is critical for the organization's growth.
The organization's Board is meeting in March with a full agenda. We will be discussing the organization's financial challenges and how we can continue to make it a stronger and more viable organization for the future.

We hope to see you at the next Walk n' Roll, Summer Picnic or at the many other activities planned this year. Your support and hard work is always appreciated.

Be safe and soon we will see Spring!

Sincerely,
Barbara Lee, Chair



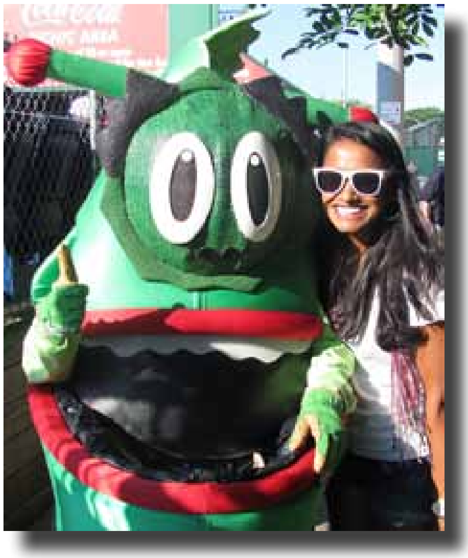


In the News

Thushy Muruges

We couldn not have done it without you!

It is with much appreciation that SBAGNE is saying goodbye to Thushy, SBAGNE Operations Associate for the last year and a half. Thushy jumped into the position, taking initiative, offering new ideas and trying to keep Ellen organized (not an easy task). Her dedication to SBAGNE, the constituents and the Spina Bifida community allowed SBAGNE to continue it's growth and expansion into Greater New England. And all she did for SBAGNE was completed while she balanced the rigors of graduate school.



We wish Thushy all the best as she lauches her future carreer. Join us in thanking Thushy for her committment and service to SBAGNE.

Mark Your Calendars!

Shake off the cold and Get Active!

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

June 27th - Hiking with Waypoint Adventures
Location TBD. All ages

Adult Clinic

SBAGNE has been participating in a series of meetings with physicians from Boston Children's Hospital and Brigham and Women's to discuss the development of a clinic service adults living with Spina Bifida. Both facilities and physicians are committed to insuring continued progress in this effort. Currently physicians in the specialty areas of urology, neurology and orthopedics have indicated interest. Watch future newsletters for additional information.

Annual Benefits Program

Due to financial constraints, the SBAGNE Board of Directors has voted to suspend the Annual Benefit Program for 2015. The Board of Directors recognizes that individuals and families often rely on these funds. This decision was not made easily and it is hoped that development efforts will permit SBAGNE to reinstitute the program in July 2015.

Jean Driscoll *Dream Big* Award

The SBAGNE Board of Directors is now accepting applications for the Annual Jean Driscoll Award. The SBAGNE offers this $1000 award as a tribute to Jean Driscoll, an eight-time Boston Marathon Champion and adult with Spina Bifida. The award may be used for educational, developmental or assistive programs and needs and will be awarded to an SBAGNE constituent, age 14 or older, with Spina Bifida who best demonstrates the character and determination of the scholarship's namesake.

Applications are due May 15, 2015.
For more information or an application visit
SBAGreaterNE.org

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 committment at this level, you lead by example and support the Spina Bifida Community. Your gift of $500 or more sustains and strenthens the work of SBAGNE. visit **SBAGreaterNE.org** for more information regarding giving levels. ***Please join today.***

URSULINE ACADEMY

Thank you!

This fall the students of Ursline Academy raised funds for SBAGNE by participating in "dress down day".

During final exam week, students at Endicott College DECA sold coffee and snacks also raising funds for SBAGNE.

Thank you to the students of both institutions for their support of SBAGNE!

ENDICOTT COLLEGE

A Call to Action

From the www.disabilityisnatural.com E-Newsletter by Benjamin Snow

I'm a 23-year-old college student with big dreams for my life! I also have cerebral palsy, and I use a power wheelchair and other assistive technology devices. I want to get through college and make a difference in the world, I like to stay up late and sleep in, and—well, I'm just a regular person. But you wouldn't know that by how some people behave.

During a recent visit with one of my grandmothers, we ate several meals in her retirement community, and were joined by my grandma's friends. At lunch in the "deli," an older gentleman and I had enjoyed a great discussion about today's politics. As we hurried off to another activity, the man asked, "By the way, how long have you been incapacitated?" I *really* wanted to stay and have a *lengthy* conversation about his choice of words—*I am not "incapacitated"*—but there was no time, so I simply replied that I was *born* with cerebral palsy.

At another meal with my grandma and her friends, the dining room hostess passed out menus to everyone except me. I was busy talking and didn't notice this until I heard my mom say, "He needs a menu, too." Did the hostess presume I couldn't read, or did she think someone else was in charge of what I eat? A few minutes later, when the server came to take our orders, she asked my mom, "What does he want?" My mom said, "I don't know; you'll have to ask him." The server *did* speak to me then, but amazingly, she seemed to "forget" several other times, so my mom and I both reminded her to speak directly to me.

Why does this happen? I don't want to believe that people are intentionally prejudicial or cruel. It seems, instead, it's a result of ignorance. Because people with disabilities have, historically, been "hidden away" behind the walls of segregated environments and/or have not participated in the mainstream of society for whatever reasons, many people *without* disabilities have had little or no social interactions with them, so when they do, it seems they simply don't know what to do or how to act!

After the events at my grandmother's, my mom and dad and I talked about these situations. My mom reminded me of similar things that have occurred throughout my life—like when I was very young, sitting in my wheelchair, minding my own business, and people asked my mom, "Can he talk?" (Why would they assume I couldn't?) She had more stories like that: perfect strangers who tried to hug me, pray over me, and/or give me money, as if I was a refugee from the Jerry Lewis Telethon! These actions seem to be the result of pity. At the other extreme are people, like the ones at my grandmother's, who ignored me. And there have been lots and lots and lots of stares, too. (My mom says she could write another book just about this stuff!)

Yes, it must be ignorance, the same kind of ignorance that people of color, women, and members of other so-called minority groups have experienced. The Civil Rights, Women's, and other Movements helped to reduce that ignorance, as people from these groups took their rightful places in schools, at lunch counters, on buses, in the workforce, and other settings in their communities.

It seems the solution to reducing ignorance about people with disabilities is the same. So this is a ***CALL TO ACTION*** to children and adults with disabilities: ***get out there and take your rightful place in society!*** The sooner more of us are out there, the more opportunities we have to educate others—*simply through our physical presence*—and the sooner others will learn that people with disabilities are regular, normal, ordinary people, too!

P.S. For proactive strategies on handling awkward situations, see "Humor to the Rescue: What Do You Say When…?" and "Why Do We Apologize?" on our family's website, www.disabilityisnatural.com.

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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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