Fall 2016

SBAGNE news

TEAM SBAGNE - 2016
FALMOUTH ROAD RACE

CONTENTS

Upcoming Events

Paint Nite

We are excited to announce that SBAGNE is hosting a Paint Nite on **Thursday, November 10** at **Pinot Palette** (7A Meriman Street, Lexington, MA) for adults (18+) living with Spina Bifida and parents of children living with Spina Bifida. Join us for a relaxed social hour from 6:30 PM-7:30 PM and painting fun from 7:30 PM-9:30 PM. The evening costs $10. Register at www.SBAGreaterNE.org (registration deadline: 11/07/16).

SBAGNE Holiday Parties

Augusta Elks Lodge
397 Civic Center Dr, Augusta, Maine
SUNDAY DECEMBER 4, 2016 12:00 PM-4:00 PM

The Party will include:
- Lunch
- Fun and Games for all ages
- Music
- Special Holiday Guest with a gift for all children attending

RSVP BY NOVEMBER 30, 2016
Include the following information in your reply:
- First and last name, phone number
- How many in your group
- Names and ages of all children in your group
- Name of person with Spina Bifida

Boston Newton Marriott
2345 Commonwealth Ave, Auburndale Massachusetts
SUNDAY DECEMBER 11, 2016 10:30 AM-2:30 PM

The party will include:
- Lunch
- Fun and Games for all ages
- Music
- Special Holiday Guest with a gift for all children attending
- Yankee Swap for the Adults

RSVP BY MONDAY DECEMBER 5, 2016
Include the following information in your reply:
- First and last name, phone number
- How many in your group
- Names and ages of all children in your group
- Name of person with Spina Bifida

Letter from the Executive Director

Dear Friends,

I hope you are enjoying this beautiful fall season, the warm days and vivid colors. As the days become shorter and a bit cooler, SBAGNE continues busy. Our focus continues to be creating a vibrant SB community, like the dazzling fall colors.

BEST (Boys, Esteem Success, Training) was held in October with five boys and their parents in attendance. This energetic group bonded from their initial meeting, playing basketball, bowling, sharing and laughing. A successful weekend!!

On November 15th SBAGNE will be holding the **Annual Meeting** at the SBAGNE office – 219 East Main St, Milford Mass. The agenda includes plans for 2017, review of the By-Laws and election of officers and directors. Board meetings are always open to constituents, please join us. If you are unable to attend – you are welcome to contact me via email or phone with ideas and suggestions. SBAGNE is a stronger organization with your input.

There is much work and planning that goes on behind the scenes to keep SBAGNE moving forward, plan and host activities. **Volunteers are needed for Board sub committees, event planning and day of event set up.** If you are interested lending a hand, contact the office for more information. Many hands make lighter work!

Mark your calendars for the upcoming **SBAGNE Holiday Parties – Sunday December 4th in Maine and Sunday December 11th in Massachusetts.** More information is available in this edition and on the SBAGNE website. Hope to see many of you there!

Enjoy the remaining days of fall.

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 area. 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** 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 update. If you are aware of an organization that should be included – please email Ellen at **edugan@SBAGreaterNE.org**.

In the News

McCourt Foundation Tour de South Shore

We could not do what we do without you! An enormous THANK YOU to the McCourt Foundation and the Holleran Family for including Team Liam's Lead Outs in the Tour de South Shore on October 1st. 35 individuals rode or walked, in the pouring rain, and raised over $26,000 for SBAGNE. This effort and support provide much needed revenue for SBAGNE. **THANK YOU TO LIAM's LEAD OUTS!**

BEST Weekend

The 4th annual BEST (Boys, Esteem, Success and Training) Weekend was held October 14-16th in Canton, Mass. The boys and parents attending enjoyed learning about service dogs, healthy living, bullying and self-defense. There was a great amount of fun as well, painting bird houses, basketball, bowling and building connections to others living with Spina Bifida. Take away quote from the weekend "You are not alone. You never have been." Jen Labesky.

2016 Year-Long Sponsors

Hollister

180° Medical

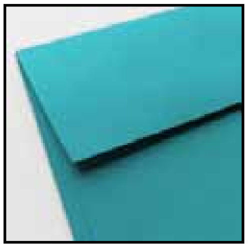
Coloplast

Friends of SBAGNE

WMS

Byram Healthcare

SBAGNE Annual Appeal



SBAGNE is again asking for your support. In the fall of each year, SBAGNE initiates the yearly Annual Appeal. The goal for 2016 is $10,000. Funds donated sustain and expand programs and services. SBAGNE is wrapping up a very successful year and looking to 2017 to continue to build community and connections. Please be a generous as possible. THANK YOU!!!!

Welcome to
amazonsmile
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.

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 Possibiility - $1000 - $2499
Circle of Promise - $500 -$999

For more details in personalized naming opportunities, please contact Ellen Heffernan at **edugan@SBAGreaterNE.org** or 888.479.1900.

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**. Applications can be downloaded at **www.SBAGreaterNE.org**.

SPOTLIGHT ON DIVERSITY

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

We love differences and diversity. When I look at the pencil cup on my desk, I love to see the different types and colors of pens, pencils, and markers at my disposal. I'm the proud owner of three different types of mechanical pencils! And check out the suitcases in my garage: I have a wide variety—different sizes, colors, and materials. My hairstyle has changed over the years; I like a new and different look every now and then. I cherish the few aspen trees that are different from the pines that fill our yard.

Everywhere we look, we love differences and diversity in: pens, pencils, cars, hair styles, computers, clothes, shoes, food, furniture, flowers and trees, telephones, music, art, vacations, weather, pets, hair spray, shave cream, shower gels, and . . . the list is endless. We seem to love diversity and differences in all things except people—specifically, people with disabilities. Before wading into the disability aspect of this subject, let's look at some examples in more detail.

When summer is upon us, some of us savor an isolated cabin by a lake for a week's worth of peace and quiet—we value simplicity. Others may prefer a busy two weeks, cramming in as much fun as possible at Disney World, Epcot Center, Sea World, Universal Studios, and every tourist attraction in between. We value nonstop excitement. These two vacations are very different *and they're both valuable.* How awful if we all had to take the same kind of vacation!

Moving on to people, our society is learning to value diversity among humans. Community events and conferences celebrate cultural, gender, ethnic, religious, age, and/or sexual orientation diversity, highlighting the value, participation, and contributions of groups who have been marginalized, devalued, or ignored.

But have you noticed that people with disabilities are usually *not* part of diversity celebrations? Why? Are they not seen as a group that has been marginalized, devalued, ignored, and worse, throughout recorded history? Don't proponents of diversity recognize that people with disabilities exist *within the groups* that are usually included in diversity celebrations? Are individuals with disabilities *invisible* to promoters of diversity?

I don't know the answers to these questions. But at a recent non-disability conference, a participant approached me after my "Disability is Natural" presentation and said, "I feel just awful! For years I've done 'diversity presentations,' and never included people with disabilities. I just never thought about them!" I appreciated her honesty, and I wondered if her attitude is common to other diversity proponents.

There's much work to be done to ensure people with disabilities are recognized as valuable members of, and participants in, our society. A first step is to educate diversity promoters. But before educating others, we need to ask them *why* people with disabilities have been excluded from the diversity movement. It's difficult to effectively educate someone if we don't understand her mindset to begin with.

We can volunteer our time and efforts in diversity celebrations. We can collaborate with others and work toward common goals. As a whole, people with disabilities have much in common with other groups who have been marginalized. You may have other ideas to resolve this issue. If so, let me know and I'll pass them on to others! When we rectify this situation, we'll make the world a better place.

But there's a bigger issue—one that probably has a more profound impact on the lives of people with disabilities than being left out of diversity celebrations. It's an issue of our individual hearts and minds.

We may publicly profess that we value and respect people with disabilities. Simultaneously, we may have great difficulty seeing the value of a particular individual with a disability (a son, daughter, student, client, etc.). So let's explore this further.

If we go back and look at the vacations described earlier, we can see that both trips—one to a simple cabin, the other to busy tourist attractions—have pros and cons. The simple cabin trip may restore our peace, but it could also lead to boredom. We *choose*, however, to put a spotlight on the positive. The busy tourist attraction trip may be great fun, but it could also be tiring. Again, we tend to minimize the potential downside, and focus on the positive.

Moreover, when people *without* disabilities speak about themselves, they almost always focus on the positives and ignore or minimize the negatives. If I want you to like and respect me, I *don't* tell you about the dirty ring in my toilet bowl, my poor math skills, or that I sometimes try to get by wearing day-old mascara! Ditto for my husband. I'm not going to tell you about the boil on his behind or other details that might cast him in a negative light. How rude and insensitive!

Yet this is what many of us routinely do when speaking or thinking about people with disabilities. We are so focused on the diagnosis and/or what a person cannot do that *we may not see* a person's strengths and abilities. Worse, we share "negative" information with others. Not only is this rude, but it amounts to a form a vicious gossip! We have the power to *ruin people's lives with our words.*

> **There is something that is much more scarce, something far finer, something rarer than ability. It is the ability to recognize ability.**
>
> *Elbert Hubbard*

Since we focus on the positives in describing ourselves (and our pets, vacations, and many more things), what will it take for us to aim the spotlight on the positive characteristics of people with disabilities? And how might this affect people with disabilities, and our society, as a whole?

We can begin by making a list of a person's strengths, gifts, and talents. You might find this relatively easy, or you may not currently see many strengths. If you're in the latter category, I suggest you look harder. Every person—regardless of the type or severity of disability—has strengths, abilities, and talents.

This activity may be easier if you first list your *own* strengths. Consider this a practice session that can get your creative juices flowing. What are *your* strengths, abilities, and talents? And how are *your differences* valuable? Are you quiet, outgoing, sensitive, bold, musical, artistic, focused, flexible, neat, or what? Do you love camping, movies, sports, animals, rainy days, funny jokes, jazz, the ocean, the mountains, the Sunday paper, or what? Are you a good friend, a budding chef, a weather-watcher, a churchgoer, a stamp collector, a good listener, a dumpster-diver, a people-watcher, or . . . ?

Once you've listed your own strengths, shine the spotlight on a child or adult with a disability in your life. If your list of his strengths doesn't grow quickly (1) think more broadly, (2) ask others who know the person, and/or (3) get to know the person better.

Come up with as many strengths as possible, over a period of time. Begin with those that come easily to mind, then put the list aside and go back to it later. A list of twenty is a good minimum. Think, think, think! Share the list with the person, and ask what he would add.

Next, think about how this list can change the person's life. Will the person look differently in your own eyes? Will he *see himself* differently? Might new possibilities for friendships, education, employment, activities, and in other areas develop? And what will happen when *your relationship* with the person is based on his strengths, instead of the perceived deficits?

Think about the relationship you have with your spouse or best friend. Healthy, positive relationships are based on the sharing of strengths. My best friend and I would not be friends for long if we continually harped on each other's weaknesses! The members of my family (including myself) would not be emotionally healthy if I focused primarily on what they can't/don't do. Thinking about most families, if we didn't *purposely* "see the good" in those closest to us, we might even decide we don't like being around them some of the time!

It takes little or no effort to see the perceived "deficits" or "problems" of people with disabilities. We may think a wheelchair, the lack of speech or hearing, behavioral traits, or other characteristics tell us something important about a person. We may, in fact, believe the disability is the *defining characteristic* of the person, and that's where our spotlight is erroneously aimed.

Isn't it time to make a *purposeful effort* to spotlight the strengths, abilities, and talents of individuals with disabilities? And isn't it also time for people with disabilities (the largest minority group in the U.S., estimated at 54 million or one in five people) to be included in celebrations of diversity?

2016 Falmouth Road Race

Thank You!

Thank you so very much to our Falmouth Road Race participants. It's people like you who make events like the Falmouth Road Race so worthwhile. Overall, we raised $32,937. We want to congratulate our top 3 fundraising teams in particular: **Brian & Dan Packard**, **Aimee & Lena Williamson**, and **Dave Balardini & Jim Lucie**. Go Team SBAGNE!

From 0 to 60: Driving and Hydrocephalus

by Krishna Jagannathan

I remember how excited my friends were in high school when they first got their license and I also looked forward to the day when I would be able to drive. For most teenagers, driving is an important rite of passage. They are no longer dependent on others to take them where they want to go. It takes a long time to become proficient at controlling the car, observing the rules of the road and exercising judgment about the appropriate response to various scenarios in the driving environment, even for an individual without hydrocephalus. Having hydrocephalus adds a whole layer of complexity to the learning process. Granted, some people with this condition do not have any major medical problems and are able to lead a normal life. Others vary in the degree to which their ability is impaired. So what do you do to prepare your teenager for this milestone given their medical condition?

Most people with serious medical conditions can buy ID bracelets which list their condition and provide information about how to contact their doctor in case of an emergency. It had never occurred to either me or my parents to get one for me because I had my last shunt revision at 11 and fortunately never had to deal with medical complications resulting from a shunt malfunction since. But it is something I would strongly recommend for teenage drivers, even if they have had no past history of medical complications. Some of the symptoms of incipient shunt malfunction can actually mimic alcohol intoxication. If a problem occurs while the teenager is driving, which causes them to be pulled over, the police may delay getting prompt medical help because they misinterpret the cause of the behavior. It's critical for the teenager to exercise good judgment by restricting alcohol intake or completely abstaining before driving to avoid such misperceptions by law enforcement (and legally, teens should be abstaining anyway). This requires open and honest communication between teenagers and parents about the teenager's role in managing their condition.

Most of my challenges in driving have come from the side effects of the condition rather than medical issues. Hydrocephalus typically affects visual acuity, coordination, judgment and concentration, all of the skills which are necessary to drive. Just learning how to coordinate between controlling the steering wheel and applying the accelerator or brake can be a daunting task when you have poor motor skills. I initially learned to drive on a stick shift, which was the car I would eventually be given to drive. Therefore, I had to coordinate shifting gears along with managing the other controls of the car. For someone like me, this was the most frustrating part of learning to drive because I did not have good coordination to begin with and seeing my friends master driving so easily affected my self-confidence. Since most cars today come standard with automatic transmission, this does not pose a problem for the teenager driver.

I still have problems judging distance or relative speed, which is a critical skill, especially in changing lanes. It always amazes me to see drivers effortlessly merging across two or three lanes of traffic on the freeway within seconds because it's a skill I have never mastered. I never drive in the leftmost "fast lane" on the freeway even if I there is a long distance to my destination, because I need a lot of clearance and time to change lanes and I am afraid that I will never be able to change quickly enough to get into my exit lane. If distance perception is a problem, the best solution is to maintain extra following distance between vehicles as well as teaching teenagers to constantly check their rearview mirror while driving to be aware of what is going on behind them.

I have trouble parking, even in clearly demarcated lanes, because I can't judge the distance between my car and the next lane once I am in the car so I end up parking closer to one side or the other instead of exactly in the middle of the space. I generally avoid parallel parking, again because I can't accurately judge whether or not my vehicle can fit into a given space. It also takes me longer to reverse out of a space when there are cars parked anywhere behind me because I can't judge how far away they are from the back of my car. As of 2016, it is mandated that all new vehicles come with a rearview camera, which will certainly help with this issue, but of course, not everyone has the finances to buy a new vehicle, nor would they want to give a new car to someone who is a beginning driver or has difficulty driving.

When I first learned to drive, I had a lot of problems with navigating by myself. All I had was a Thomas Brothers physical map. So if I wanted to get from one point to another, I had to chart my route out on the map first, then write it down and commit it to memory. People with hydrocephalus can sometimes have difficulty telling the difference between left and right. On a map, of course, left and right are correlated with cardinal directions: north, south, west and east. If I am figuring out how to get somewhere, it isn't enough to tell me to go west 2 blocks and then turn right, for example because I have no sense of what "west" means in terms of where I am currently located. Navigating while driving doesn't allow a lot of time to process and convert directions to an easily comprehensible form. Of course, now smartphones have GPS so route guidance can tell you when and where to turn and even re-direct you in case you miss the turn. It's definitely a worthwhile investment to have some form of automated navigation system in the vehicle that the teenager will be driving.

Hydrocephalus can also affect memory. Even though I have lived in the same city all my life, except for familiar routes which I travel on a daily basis, I still have trouble navigating without GPS even if I have been to a place frequently before in the past . Before I go somewhere for an appointment, I usually do a preview drive the day before. While GPS may get me to the actual address, I still need to familiarize myself with where to park, how to get from the parking area to the place where my appointment is and anything else that may interfere with finding my way, like construction activity. Anything that deviates from my expected route creates problems for me so I always have to plan ahead. I am currently self-employed, but it would have been a serious obstacle in my career if I had to for work and was expected to drive in new cities to get to a conference or a client meeting but didn't have the time to prepare in advance.

Driving at night is one of the skills a teenager should be comfortable with before getting a license. Just getting experience behind the wheel is insufficient because hydrocephalus can affect vision. For a long time, I used to avoid driving at night, because I could not see very well. Many high-end vehicles now have an array of technology available to assist drivers, including adaptive headlights, adaptive cruise control and braking, blind spot monitoring and lane departure systems. (Car and Driver new night driving features.) In time, these may be standard features in all cars, allowing teenagers with hydrocephalus to experience the same freedom and mobility as their peers without experiencing undue anxiety, as I did.

Compounded with problems judging distance and depth, I was afraid of making mistakes because I could not accurately distinguish the road in front of me. At first, I had to have someone else with me in the car. Of course, that is not always possible on a daily basis. Over time with continued practice, I am fairly comfortable driving along routes I normally travel in the daytime. It does impact my social life, though. I can't meet friends for dinner or other social activities at places that fall outside my travel radius unless they are willing to come and pick me up. I also can't offer to drive other people at night, so most of my socializing has to occur during daylight hours. I have learned to accept these limitations but there are other options available.

Programs for vision therapy can help people who have difficulty with depth perception, seeing things in 3D and other associated visual problems that are common in those living with hydrocephalus. If you choose to pursue vision therapy for your child, the therapy should be started with children with visual deficits well before they begin learning to drive because the same problems affect other areas of their lives like reading and athletic ability. Although having hydrocephalus can make learning to drive more challenging, there are many resources available to help a beginning driver deal with the limitations of their condition and to allow them to live as normal a life as any other individual without those limitations.

Krishna is a new guest blogger for the Hydrocephalus Association. She is private tutor, a mom of two beautiful children, and an adult living with hydrocephalus.

Reprinted with permission from the Hydrocephalus Association.

Contacts

SBAGreaterNE Tel. (Toll-free)	**(888) 479-1900**
SBAGreaterNE Tel. (Toll)	**(508) 482-5300**
SBAGreaterNE Fax	**(508) 482-5301**
SBA Tel. (Toll-free)	**(800) 621-3141**

Board of Directors

Chair
Rebecca Sherlock
Email: **rsherlock@SBAGreaterNE.org**

Vice Chair
Ginny Briggs
Email: **gbriggs@SBAGreaterNE.org**

Treasurer
Linda Long-Bellil
Email: **llongbellil@SBAGreaterNE.org**

Clerk
Jason Paynich
Email: **jpaynich@SBAGreaterNE.org**

Dr. Stuart Bauer
Email: **sbauer@SBAGreaterNE.org**

Abigail Bordeaux
Email: **abordeaux@SBAGreaterNE.org**

Emily Cooke
Email: **ecooke@SBAGreaterNE.org**

Shannon Cutter
Email: **scutter@SBAGreaterNE.org**

Aimee Williamson
Email: **awilliamson@SBAGreaterNE.org**

Operations

Ellen Heffernan-Dugan (888) 479-1900
Executive Director
Email: **edugan@SBAGreaterNE.org**

Laura Lambert (888) 479-1900
Operations Associate
Email: **llambert@SBAGreaterNE.org**

Elizabeth Brodeur (888) 479-1900
Administrative Assistant

Contacts

Empowerment Program
Ellen Heffernan-Dugan, Executive Director
E-mail: **edugan@SBAGreaterNE.org**

Falmouth Road Race
Ellen Heffernan-Dugan, Executive Director
Email: **edugan@SBAGreaterNE.org**

Fund raising
Ellen Heffernan-Dugan, Executive Director
Email: **edugan@SBAGreaterNE.org**

Membership
Ellen Heffernan-Dugan, Executive Director
Email: **edugan@SBAGreaterNE.org**

Memorial Donations
219 East Main St (888) 479-1900
Ste 100B
Milford, MA 01757

Parents Helping Parents
Cara Packard
Email: **cpackard@SBAGreaterNE.org**

Youth & Adults Group
Ellen Heffernan-Dugan, Executive Director
Email: **edugan@SBAGreaterNE.org**

Walk-n-Roll
Ellen Heffernan-Dugan, Executive Director
Email: **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.

Spina Bifida Association of Greater New England
219 East Main St
Ste 100B
Milford, MA 01757

Toll Free Phone: (888) 479-1900
Web site: **www.SBAGreaterNE.org**

NONPROFIT ORG
US POSTAGE PAID
DUNSTABLE MA
PERMIT NO. 20

CHANGE SERVICE REQUESTED

Without your correct address (mail or e-mail), we can't contact you, send you the newsletter or let you know about upcoming events. If you move, please e-mail or call Ellen Dugan with your updated information.