Fall 2017

SBAGNE

news

Liam's Lead Outs Ride for SBAGNE!

2017 Tour de South Shore

SBAGNE
news

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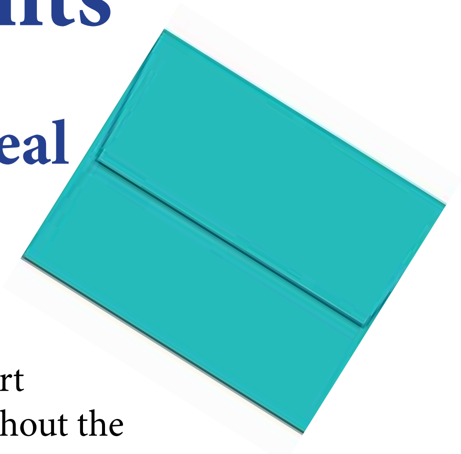
SBAGNE is a group of parents, adults and children with Spina Bifida and dedicated professionals working together to support and encourage families and individuals throughout the Greater New England area. It is our goal to enrich the lives of those affected by Spina Bifida through education, parental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

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

Upcoming Events

SBAGNE Annual Appeal



Watch your mail for the teal envelopes!

In the Fall of each year SBAGNE initiates the **Annual Appeal**. The goal for 2017 is $6000. Funds donated support SBAGNE Programs and services throughout the year. Looking forward to 2018, SBAGNE will continue to focus on supporting connections, advocacy, education and support.

PLEASE JOIN THE CIRCLE OF SUPPORT - BE AS GENEROUS AS POSSIBLE. Thank you!!!

Annual Thank-A-Thon

During the month of November, Board Members will be reaching out to thank our very generous donors. SBAGNE could not accomplish all that we do without your support. This is also an opportunity to share with Board Members thoughts regarding ways in which SBAGNE can serve you and the Spina Bifida Community. We look forward to receiving your input.

Empowerment Program

Our Empowerment Program is open for applications. You are invited to apply for our Empowerment Benefit Program. The benefit may be used for reimbursement for adaptive equipment, camps, 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 or younger who are living with Spina Bifida are eligible to apply. Visit **www.SBAGreaterNE.org** for more information or to apply.

Letter from the Executive Director

It has been a fast three months since being named as the new Executive Director. I want to take this opportunity to thank you for welcoming me into the SBAGNE family. As a child growing up in Rhode Island, I heard about what was then SBA Massachusetts and how great of an association it was. I'm glad that the only thing to change since then was the name! This is a great association and we have many things to be proud of. Over the next few months be on the lookout for surveys and questionnaires for you to fill out about SBAGNE and what you'd like to see happen within the organization. After all, this association is here for you!

Last but certainly not least, Ellen, I want to thank you for your years of service to this association and community! You will be greatly missed. Enjoy retirement on Cape and read a good book for us!

Andrew

Board Openings

Thinking about how you can give back to the Spina Bifida community? SBAGNE's board is accepting applications. Apply to the Spina Bifida Association of Greater New England's Board of Directors. For more information or to apply, contact Executive Director, Andrew Vacca at **avacca@SBAGreaterNE.org** or 888-479-1900.

SBAGNE Circle of Strength

When you make a donation of $500 or more, you're 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**

In the News

Tour de South Shore

SBAGNE would like to thank Dan, Mary and Liam Holleran and the entire Liam's Lead Out team for an amazing turnout for the 2017 Tour de South Shore. The entire Holleran family took the idea of "lead out" seriously and were able to raise over $30,000 for SBAGNE! (Look up the term "Lead Out" in cycling.) Please join us in thanking them for their efforts and maybe consider joining the Liam's Lead Out team for the 2018 Tour de South Shore! Check out the photo on the cover!

BEST

BOYS · ESTEEM · SUCCESS · TRAINING

We had a great weekend at BEST a few weeks ago! We had seven boys attend and had two young adults living with Spina Bifida in the role of mentors this year. Yes, we had a blast using the gym and bowling alley at Pappas Rehab and we also have budding musicians in the group. Check out Grayson's rap in this video from BEST(**https://youtu.be/IKvsXn4GzQY**). But what was awesome to see was that the two mentors that attended stepped into their roles and by the end of the weekend the boys really were looking up to the two mentors and one boy said he wanted to take them home! We're looking forward to BEST again next year and hope to see you there!

Parents: Privacy...Please!

by Kathie Snow, www.disabilityisnatural.com

My computer dictionary defines privacy as: "The state or condition of being free from being observed or disturbed by other people; the state of being free from public attention." Privacy is important to all of us, in many different ways.

Most of us, for example, don't want our medical information exposed to every Tom, Dick, and Harry. To that end, we're all protected by HIPAA (Health Insurance Portability and Accountability Act of 1996): "The Privacy Rule sets rules and limits on who can look at and receive your health information."

Parents of children with disabilities have further privacy protections for their children in the special ed system: FERPA (Family Educational Rights and Privacy Act of 1984) is "a federal privacy law that gives parents certain protections with regard to their children's education records, such as report cards, transcripts, disciplinary records, contact and family information, and class schedules."

Yet the privacy of many children with disabilities is violated 24/7/365 by those closest to them—their parents! The most intimate, personal, and private information overflows on social media, blogs, websites, comment areas, etc.

You lose your privacy, and sometimes, people don't see you as human.
Shawn Wayans

While the internet has provided valuable opportunities for parents to connect and learn from each other, the detailed sharing of our children's lives has been going on long before the advent of social media. As a presenter in the disability arena for 25-plus years, I've witnessed parents meeting each other at conferences and within minutes, their conversations are focused on their children's diagnoses and problems. This is duplicated in today's "sharenting," as it's now called: parents seldom share anything *positive* about their children with disabilities. When I'm speaking at a conference, it's common for parents to share with me, either in front of the entire audience or one-on-one during a break. About 99 percent of the time, the parent begins the conversation with the child's diagnosis and a laundry list of problems. I gently interrupt and ask, "What is your child's name?" "Oh—her name is Emma..." Then I ask, "Can you tell me three wonderful things about Emma?" And the vast majority of parents say . . . nothing. They're unable to readily share anything positive about their children.

It's important to recognize that parents are not being intentionally unkind about their children. We have been "trained" by the disability service system to focus on diagnoses and problems because those are the eligibility criteria for services. Further, seldom do professionals in Early Intervention, Early Childhood, Special Ed services, etc., help parents identify or focus on their children's strengths. So we, as parents, may inadvertently adopt the deficit-model thinking and talking practiced by professionals. At that point, our children's strengths and abilities become invisible to us!

How can our children be successful, today or in the future, if we don't identify, believe in, and share their capabilities, talents, and potential? They see themselves through our eyes. What do they see?

Adding insult to injury, too many parents broadcast the "bad news" about their children to the world via social media. Again, they don't *intend* to cause harm. Some parents are genuinely trying to learn or share information about therapies, interventions, treatments, and/or strategies that may be helpful for their children. Other parents, however, seem to use social media as a "woe-is-me" platform; competitions about whose life or whose child is "worse" or "better" are common.

Our *intentions* don't matter; *outcomes* matter. Remember the axiom we're all familiar with: "The road to hell is paved with good intentions." So before posting one single word about our children have we considered the outcomes? Posting your child's name and birth date, announcing a birthday party, or sharing about other activities could lead to identity theft or knowledge of where your child lives. Photos could be "stolen" and reposted by pedophiles, by cruel people who make fun of children with disabilities, or even by an unbalanced individual who may identify your child as *hers!* And a "closed" group is no guarantee: we have no idea what our "friends" may do with our information.

Would you share that your partner recently started taking Viagra or that your burly 16-year-old son still needs a night-light in his bedroom? Can you imagine their pain if you violated their trust? If we agree that sharing this type of information is wrong, why is sharing intimate information about a child with a disability acceptable?

Have we considered that what's been posted on the internet essentially lasts forever? By the time a young child with a disability is an adult, she might have an electronic footprint that extends far and wide. What might happen when she enrolls in post-secondary education or applies for a job, and her social media presence is reviewed? What about the possibility that people in the disability service system might search social media for you/your child and discover information that impacts your child's services now and later?

Have we asked our children for *permission* to share their lives with the world? What if the positions were reversed? Would it be okay for your child to share *your* personal, private information or to post questions about "how to deal with a blabber-mouth mother"?

Are our children *aware* of what we've posted about them? Younger children maybe not so much; but older children? At some point, the child *will* see and/or hear about what parents/family members have posted. Will your child *thank you* for revealing her private details to others? When she's 20, how will she feel about a lifetime of her parent's blabbing? What can she do to regain her privacy? (Not much, sadly.) If we haven't asked the child's permission, we shouldn't be surprised if the child is deeply hurt, embarrassed, ashamed, and/or angry! Trust between the child and parent may be irrevocably damaged. The benefits of social media to the parent seem to pale in comparison to the harm caused to the child.

> **All violations of essential privacy are brutalizing.**
> *Katharine Fullerton Gerould*

In my books, articles, and presentations, I *do* share lessons from my son's life that might be helpful to others, but *only* if my son has given his permission. When "something new" happens in Benjamin's life, I ask if I can share it, and if he says no, the story remains private.

That's the first step parents can take: ask your child's permission before posting anything on the internet. Would you consider removing everything you've posted about your child and then start again with a clean slate? When you ask your child's permission, if she cannot understand because of age, communication issues, or how the disability affects her, err on the side of caution and assume your child would say no! You may decide to ask again at a later time, but a child's inability to understand or answer the question doesn't give us license to carelessly plow ahead.

If you use social media to learn about and/or to share about your child's diagnosis, condition, or situation, mask your child's identity to protect his safety and dignity. You should still seek your child's permission and ensure that whatever you post will not be hurtful to your child at any point in her life.

Perhaps you could use social media only for an introduction to others, then conduct your "business" via email or phone, privately. And if your email signature or other identification is something like, "Linda, mom to Trisomy 13" or "Susan, autism mom," please, please consider a new moniker that doesn't reference the diagnosis. Your child does not want to be known by the diagnosis (it's not the defining characteristic of your child) and she does not want *you* to be known that way, either.

Maybe you'll decide that social media is taking up too much of your valuable time—precious time that could be spent doing wonderful things with your family, focusing on your child's strengths and abilities, and making cherished memories. Our children's childhoods are fleeting and every moment counts.

There's much more to consider than what I've detailed in this brief article. Search for "sharenting" on the internet and you'll find more on this topic to thoughtfully consider.

Under HIPAA and FERPA, parents have legal recourse if their child's privacy is violated by professionals. What rights do children have when their *parents* are the violators? How do our children *feel* about their private lives being shared publicly? Shouldn't we care?

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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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