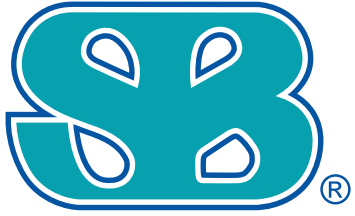


Spring 2017



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 today to contribute.

Upcoming Events

2017 Walk N Roll Announced! June 3rd

SBAGNE's annual Walk-N-Roll will take place this year on June 3rd.

Register your team today! We need your support!

RAISE OR DONATE \$1000 for the opportunity to hit Rebecca Sherlock or Ellen Dugan with a PIE IN THE FACE!

Visit 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.

Are you a runner or do you know someone who would like to participate in the Falmouth Road Race and support SBAGNE ?

Contact **Laura Lambert** at llambert@SBAGreaterNE.org

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

Summer Picnics! July 15th (Massachusetts) and August 5th (Maine)

Can you believe it! The Summer Picnics are right around the corner. Please see the enclosed insert for location and registration details.

Letter from the Executive Director

I hope all are enjoying the first warm days of spring! SBAGNE has been busy planning events and activities for the coming months. If you have not already done so – visit SBAGreaterNE.org and register yourself or your team for the Walk N Roll for Spina Bifida – June 3rd in Canton Mass. Two exciting happenings will occur at this year’s Walk N Roll. If you raise or donate \$1000 you or someone you choose will have the opportunity to try to hit **Rebecca Sherlock**, Board Chair or **Ellen Dugan** with a pie in the face. This is a once in a life time opportunity, 2017 is Rebecca’s last year as Board Chair and I retire June 30th. An opportunity not to be missed. Also, we will be having a special guest appearance by Elvis!! Elvis will perform, be available for photo opportunities and will lead off the Walk. This is SBAGNE’s biggest fundraiser of the year. We need your support to continue supports and services. Are you registered, do you have a team?? If not, plan now to join the SB Community of Greater New England on June 3rd register now at SBAGreaterNE.org.

Activities for adults, ages 18 +, living with Spina Bifida are planned for June. More information to come. **Summer gatherings** are planned for Massachusetts and Maine -watch your email and the SBAGNE website for more information.

SBAGNE relies on community and fundraising events, to raise awareness and funds. Do you want to do an event in your community - raise awareness and funds in support of SBAGNE? Looking for ideas? We would be happy to assist you in brainstorming ideas that would be a good match for your community, work or school. Contact us at edugan@SBAGreaterNE.org or llambert@SBAGreaterNE.org.

Hope to see many of you at an upcoming events.

Best,
Ellen



Thoughts from BLIN’G

We had an amazing time at BLING weekend! The entire time we had something to do and were having so much fun. Being Mackenzie’s 18-year-old sister rather than her parent, I was worried about sticking out in the parents’ group, but I had a lot of fun, made friends, and learned a lot. It began with Mackenzie staying by my side the whole time and not wanting to be separated when the kids were doing activities separate from the parents. By the next morning, she was sitting at a table without me, surrounded by all her new friends. She even cried when it was time to leave because she was going to miss everyone so much. I am so happy we could go because not only did I learn a lot about caring for her and got to hear from other families in our situation, I know that Mackenzie had an amazing time and learned a lot. The activities planned for us kept us having fun and entertained the whole weekend, and we can’t wait to go back.

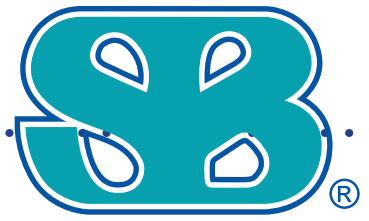
Sincerely,
Kelsey

BLING weekend was the best weekend ever! I made so many friends, who I miss so much and I want to FaceTime with soon. My favorite activity was playing shark tank, because we learned about spina bifida and made future inventions. I was nervous at first when Kelsey went with the parents, but everyone was so nice to me and we were having too much fun to be nervous. I also loved the last day when we got to do our hair and makeup, and I can’t wait to go back!

Sincerely,
Mackenzie

Check out the BLING photos at SBAGreaterNE.org!

In the News



Rock on!

by Andrew Vacca

Climbing a rock wall was something that I thought would not be possible. **Waypoint Adventure** happily proved me wrong! They explained the process of climbing the wall and also gave me the equipment I needed to do just that! It was most assuredly a challenge, in the first few steps up the wall were hard, but the sense of accomplishment I felt when I touched the top of the wall is a feeling I will not soon forget. This experience encouraged me to continue to try new things even though they might be hard and push myself to see what I can do and see how far I can go.



Resources

National Center for Medical Home Implementation

A medical home is a method for ensuring comprehensive, accessible, family-centered care that supports a child continuously from infancy to young adulthood and provides transitional assistance upon reaching adulthood. Through various partnerships, the National Center for Medical Home Implementation works to secure access to a medical home for all children and youth who may benefit from one. Visit <https://medicalhomeinfo.aap.org/Pages/default.aspx> for more details.

CaringBridge

CaringBridge is a website-building platform meant for people who wish to share health updates about themselves or a family member with friends and loved ones in a quick and convenient manner. The site is user-friendly and allows for personal stories, updates, and well-wishes to be shared. Individual sites can be connected to GoFundMe for people raising funds to cover additional medical expenses. Build your own site at: <https://www.caringbridge.org/>.

DCU Access Loans

DCU Banking offers Access Loans, specific to the purchase or payment of any product, device, or building modification designed to assist someone with a disability. The borrower is not required to be the beneficiary and purchases may include: powered non-vehicle transportation, manual transportation, adaptive computer and communications equipment, and kitchen, bathroom, or other home modifications among other relevant purchases. Terms are up to 72 months and can include loans from \$1000-\$25,000. For details, visit: <https://www.dcu.org/loans/access.html>

Bank of America Access Loans

People living with disabilities who have special vehicle needs are eligible for a Bank of America Access Loan. This auto loan assists with the purchase of an accessible car, van, or light-duty truck or with the modification of an existing vehicle. To learn more, go to: <https://www.bankofamerica.com/auto-loans/disability-access-loans/>

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.

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.

The Good PCA and Your Health

By Raymond Glazier

Only a seasoned PCA consumer knows how vitally important a good PCA is to the consumer's health and vitality. Among the crucial care tasks that come to mind are safe transfers (safe for both parties), skin care and skin integrity checks, accurate meds maintenance and administration, thorough and consistent regular bathing. And then there are items not so survival critical, like careful dressing and grooming (not only for the lady consumer), maintenance of a clean and orderly home environment, and honest and accurate record keeping. How to find the Good PCA?

In previous columns we have touched on PCA recruiting, for which each MassHealth PCA Program consumer receives training from the Personal Care Management (PCM) agency through which services are provided. Crucially important in a PCA candidate is some familiarity with the Independent Living concept. For this reason, I have usually steered clear of individuals with a health care background or health care experience. For the most part, they just don't get it; they are more accustomed to working on people, not with them. Secondly, the PCA candidate's health status is a legitimately paramount consideration. A PCA who is incapacitated by a chronic or episodic physical or mental illness cannot be relied upon. Many PCA positions also require a measure of physical strength, depending upon the consumer's care plan and specific needs.

The qualities to look for in a good PCA candidate include those one would want in any employee — integrity, honesty, reliability, responsibility. But these desired characteristics take on a new dimension when this is the person who will be getting you out of bed, toileted, showered, and dressed each morning, as well as preparing your meals, cleaning, shopping, and running errands, etc. The ideal PCA also has the qualities of a trusted friend — caring, concerned, patient, forgiving, loyal.

A consumer new to depending on PCAs may, as I once did, look for the one perfect PCA who can be all things and do it all. It just doesn't work that way: Even the perfect sole PCA will inevitably need a sick day or a personal day to accommodate, for example, a heavy date, a doctor appointment, a time-critical personal errand, an important exam. For this reason and because any one person has a limited skill set, I advise having multiple part-timers sharing the duties and the schedule, if ones approved hours permit.

No PCA is perfect, but good ones, while somewhat hard to find, are definitely keepers. So it behooves the enlightened consumer to look out for PCAs' health. MassHealth does not offer health insurance to PCAs, although that might contribute substantially to stabilizing the PCA workforce. A somewhat dated state survey study found that the majority of PCAs do have health insurance, either through another family member or coverage on another job. Two unrelated, independent PCAs with complementary skills and different schedules are preferable, in my opinion and in my decades of experience.

Some mutually beneficial good preventive health practices for you and your PCA include thorough annual physicals, regular checkups, annual flu shots, healthy eating, a sound sleep regimen, and daily exercise. For the consumer, daily exercise includes stretching and repetitive range of motion for all immobilized joints, while transfers, other daily living tasks for the consumer, and doing passive exercises all contribute to your PCA's exercise regime. I often jokingly tell my PCAs that I should be charging them gym membership fees.

Raymond E. Glazier, Ph.D. has decades of professional experience studying PCA issues, as well as decades of personal experience as a consumer in the MassHealth PCA Program. He is a principal of disAbility Research Associates LLC and welcomes comments or questions at ray_glazier@post.harvard.edu.

Healthy Skin Starts with You!

by Cathy Caillouette

Keeping skin healthy is important for anyone, of any age, with a loss of mobility or sensation, such as in Spina Bifida. Skin injuries from pressure can be quite troublesome. This article will remind you how to care for your/ your child's skin, and how to prevent some common skin injuries.

Take a Look!

Skin care and skin checks should be part of your daily routine. Keep your body clean and dry. Use gentle moisturizer on dry skin areas, and keep skin folds (where skin touches other skin, such as your hip area) dry. A mirror or someone's help may be required to look at the areas you can't easily see. Pressure ulcers/skin injuries usually develop in bony areas and/or areas where there is no sensation, so pay close attention to these areas! Children as young as toddlers can start to assist in their own skin exams.

Be aware of danger signals-such as a red or purplish area that does not fade after 10 or 15 minutes once pressure is removed. This is a sign that the skin and the tissues underneath may be damaged from pressure. Other danger signals are open wounds, tears in the skin, areas of thick dry skin (also known as calluses), and blisters.

Equipment should also be checked daily. Braces or shoes that don't fit well and broken wheelchairs or wheelchair cushions can all cause skin injuries.

Protecting Your Skin

The following will help prevent skin injuries, no matter your age!

- Keep your equipment and braces in good condition
- Update your equipment as you grow or your body changes
- Weight shifts every 15 minutes, overall position changes every 1-2 hours
- Avoid dragging your body or body parts
- Have a good bowel/bladder program to avoid frequent wet skin
- Have good fitting shoes, and check feet and inside your shoes frequently
- Wear dry socks
- Keep a healthy weight-eat nutritious foods and stay hydrated
- Avoid smoking

Treatment

If you find a trouble spot (such as open skin, blister, red/purplish/darker skin area), you should seek medical care. Recognizing and treating problems early can help avoid later complications! Your Spina Bifida team, primary care provider, or specialists such as podiatrists, plastic surgeons, and/or physical therapists can all aid in the prevention and treatment of troublesome skin issues.

Cathy Caillouette, MS, CPNP, CWON is a Pediatric Nurse Practitioner at Boston Children's Hospital. She can be emailed at Catherine.caillouette@childrens.harvard.edu.

The information in this article 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.

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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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