Spring 2016

SBAGNE news

BLING

Better Living n' Girls

WALK-N-ROLL FOR SB

new balance FALMOUTH ROAD RACE 2016

SBAGNE
news

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Events

Adult Get Together: Bertucci's - Newton, MA

Saturday, May 14th, 1:00-4:00 PM - 275 Center St, Newton, MA

Join SBAGNE friends for lunch (1:00 PM). Visit old friends, meet new friends, enjoy great food!

RSVP no later than Wednesday, May 11, 2016 online, by e-mail to **edugan@SBAGreaterNE.org** or call 888-479-1900.

Kayaking

Tuesday, July 12th - Lower Mystic Lake, Medford, MA

Join SBAGNE and Waypoint Outdoor Kayaking for a 2 mile paddle on one of New England's most beautiful lakes. Visit **SBAGreaterNE.org** for more information and to register today.

Maine Summer Picnic

July 30, 2016 - Maine Wildlife Park, 56 Game Farm Rd, Grey, ME

SBAGNE will be hosting a picnic at the Maine Wildlife Park. Lunch will be provided and there will be activities and surprises for all ages. A covered and accessible pavillion along with accessible restrooms will be available. Please RSVP by July 25, 2016 and visit **SBAGreaterNE.org** to register today.

new balance
FALMOUTH
ROAD RACE
2016

Sunday - August 21, 2016

We would like to happily announce that SBAGNE will once again participate in the annual New Balance Falmouth Road Race! Our organization will have a running team for the 2016 race.

Last year we had a dedicated team and we had a highly successful fundraising campaign with $40,000 raised. We are looking for runners that are as passionate about raising awareness on spina bifida as they are running.

We currently have 9 entry slots open to interested runners. If you are interested, please make contact soon, we would hate to have an interested runner miss out on a spot.

If you are interested, contact Jeff at **jvendetti@SBAGreaterNE.org**.

Letter from the Executive Director

Dear Friends,

There is a chill in the air despite the calendar telling us that it is Spring here in New England. As there are signs of new growth and renewed energy, we are busy planning Spring and Summer activities.

On June 4th, SBAGNE is hosting the 7th Annual Walk-N-Roll for Spina Bifida in Canton, MA. This family friendly walk is a non-competitive, 1.5-mile walk event and educational resource fair that raises awareness of spina bifida and celebrates the accomplishments of American living with its challenges. The name "Walk-N-Roll" was selected because it embodies a sense of inclusiveness and invokes the sense of empowerment which the Spina Bifida Community embraces in all that it does. Funds raised are vital to support SBAGNE programs and services in greater New England.

Register now at **www.SBAGreaterNE.org**. Looking forward to seeing you there!

A small group of adults met at the Museum of Science on a Saturday in February for lunch and a movie in the Omni Theater. Additional get togethers are being planned and I need ideas for activities and locations. Lunch, movies, bowling, paint nite, please share your ideas!

WE NEED YOU! Committees are vital to maintaining the strength and efficiency of SBAGNE. If you have an area of expertise or interest that would benefit SBAGNE, Committees typically meet monthly, via conference call. Calls are generally planned for a time in the evening and are approximately an hour in length. SBAGNE has 3 committees - 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. Many hands make light work!

Know that we continue dedicated to providing the support and programming that are at the core of our mission. If you have ideas about how you think SBAGNE could better serve the needs of individuals living with spina bifida and your family members, please let me know (**edugan@SBAGreaterNE.org**).

Be well,

Ellen

Ellen Dugan, Executive Director, SBAGNE

SBA National Conference, Minneapolis, Minnesota

SBA of Greater New England will be awarding 4 Conference Scholarships of $1200 each. For more information and to apply, please go to: http://sbagreaterne.org/programs-services/financial-programs/sba-conference-awards/

Resources to Fund SBA Conference Attendance

The Development Disabilities Councils of Vermont, Massachusetts, and New Hampshire provide limited funds to assist in attending a conference.

For more information on your particular state, please click on your state's link.

Vermont: **http://www.ddc.vermont.gov/**
Massachusetts: **http://www.mass.gov/anf/employment-equal-access-disability/oversight-agencies/mddc/**
New Hampshire: **http://www.nhcdd.org/**

CLUBS AND ASSOCIATIONS

Some charitable organizations offer scholarships or grants for constituents to attend medical conferences. Many of the following organizations have a local chapter and would best be sought after at that level.

- Chambers of Commerce
- Rotary Clubs
- Native sons of the golden west
- Kiwanis
- Elks Clubs
- Daughters of the American Revolution
- Veterans of Foreign Wars
- Lions Club
- YMCA
- YWCA

FLEXIBLE SPENDING ACCOUNTS

The IRS allows Flexible Spending Accounts (FSA) to be used to attend medical conferences. FSA funds can be used for admission and transportation to a medical conference if the individual or immediate family member has the condition that the conference is related to. If you or any of your family members participate in FSA's at your place of employment you can use the money in your FSA as a stipend to attend Conference.

INDIVIDUAL WITH DISABILITIES EDUCATION IMPROVEMENT ACT (IDEIA)

Each year, money is set aside in the IDEIA budget to support parent involvement. This money is used for parents who have children with disabilities and special needs and can be used stipends to attend medical conferences. You will need to engage with the local Director of Special Education or the District Superintendent to ask them to sponsor your attendance to the conference as a parent with IDEIA assistance funds.

In the News

Jean Driscoll "Dream Big" Award

Application Deadline - May 15, 2016

The Spina Bifida Association of Greater New England's Board of Directors are now accepting applications for the 2016 Jean Driscoll Award. This $1000 award, offered by SBAGNE, 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.

Jean Driscoll, who was born with Spina Bifida and has used a wheelchair since her early teenage years, is an accomplished athlete and speaker known around the world, is who this award is named after. Jean is an Olympic athlete who has won Silver medals in both the 1992 and 1996 Summer Olympic Games and a world record holder in the 10,000 meter track event, 10K and marathon road racing distances. She has also won the Boston Marathon eight times and is the only person in Boston's 105 year history to achieve this feat.

We at SBAGNE believe this award will allow a person living with spina bifida reach to "DREAM BIG"

For those who would like to apply for this award please go to the "Financial Programs" section at **SBAGreaterNE.org** or contact **jvendetti@SBAGreaterNE.org** for an application.

Spotlight on SBAGNE

Jason Paynich - SBAGNE Board Clerk

Professor Jason Paynich is currently the senior faculty member in the Criminal Justice Department at Quincy College in Quincy, MA. After working as a municipal police officer in Montana, Jason earned a Master of Science in Criminal Justice Administration from Minot State University where he focused on police research and methamphetamine prevention. Jason moved to Massachusetts in 2004 with his wife and 3 kids, the youngest having spina bifida. He is an active member of the SBAGNE Board of Directors, as well as the International Association of Crime Analysts, the Academy of Criminal Justice Sciences, and several other professional associations. His hobbies include flying drones, outdoor activities, motorcycles and woodworking.

Rock Climbing for SBAGNE

by Enock Glidden

As a person born with Spina Bifida I have been very lucky to find people that wanted to challenge me and push me to try new things. As a result I have been able to have some amazing experiences and be able to achieve a lot of awesome goals. I have been able to learn how to fly airplanes, go skydiving, wheelchair race, and play on a wheelchair basketball team.

I am now embarking on a new adventure. I have been able to learn different rock climbing techniques after seeking out a way to make it possible. I found an organization called Paradox Sports. With their help and guidance I have been able to work my way toward climbing El Capitan this fall 2016. El Capitan is a vertical rock formation in Yosemite National Park. The granite monolith extends about 3,000 feet from base to summit along its tallest face and is one of the world's favorite challenges for rock climbers

I will be using the climb to raise money for SBAGNE to help others achieve their goals and dreams of doing the things that make them feel alive and give them a sense of achievement.

WALK-N-ROLL FOR SB®

Walk-N-Roll - Saturday, June 4, 2016
Mass Hospital School, Canton, MA
Family, Friends, Fun & Great Incentive Gifts!
Join Us for Walk-N-Roll for Spina Bifida help us reach our goal

$60,000

For those new to SBAGNE, the Walk-N-Roll for spina bifida is a family-friendly, walk event being held in various locations across the country to raise awareness about spina bifida and celebrate the accomplishments of the over 180,000 Americans living with it . All proceeds are used for programs and services for people living with spina bifida.

This year's walk will take place at the Massachusetts Hospital School in Canton, Massachusetts on Saturday, June 4, 2016.

Can you raise $500 or more? If you answered yes, you can be a Walk-N-Roll Superstar!! Our special Superstar program recognizes and honors people who go above and beyond by donating or raising $500 or more for the Walk-N-Roll. As a Walk Superstar, you will receive recognition in the SBAGNE newsletter, SBAGNE social media and special star signage on the walk route. Superstars lead the way for the SBAGNE to expand our initiatives and services for individuals living with spina bifida, their families and supporters.

To sign up or to donate, please go to: **http://sbagreaterne.org/2015-walk-n-roll-for-spina-bifida/**

Thoughts on BLIN'G 2016

This year we attended our 4th Bling, and it was the best time yet. From the very first, my daughter felt amazed to get together with a fantastic and diverse group of girls who really understood what her life has been like. Although naturally reserved, she's blossomed in recent years—reaching out and making new friends. She's so relaxed, knowing that anything she says will be understood and accepted; there's never any worry about feeling different or being judged.

BLIN'G has been a much needed retreat for me as well. Just being able to voice concerns and seek advice from other moms who've been through it all is invaluable. Another benefit is the ability to discover new services, adaptive equipment, and adaptive experiences for my daughter to participate in. The time to relax and connect with others provides a source of incredible stress reduction and helps me do what's best for my child in the coming year. I'm so grateful that we found our way into the wonderful community that gathers each year at BLIN'G!

~ Christine Row

I love the BLIN'G weekend. It's a great opportunity to have fun, relax, and socialize with other girls who have spina bifida. It makes me happy to have a place to talk about spina bifida where I am not singled out because of it. We're all on the same page here. Sure I love the makeovers and the Reiki massage, but it's really talking (and laughing) with other girls who have Spina Bifida that makes me feel at home and like a normal person - something I don't always have the luxury of feeling.

~ Kaileigh Row

BEST 2016

Friday, October 14th - Sunday, October 16th

BEST is for young men, living with Spina Bifida, ages 10 -15

More details and registration now available at **SBAGreaterNE.org.**

Questions? Contact Ellen Dugan at **edugan@SBAGreaterNE.org**

Support SBAGNE Committee Volunteers Needed

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.

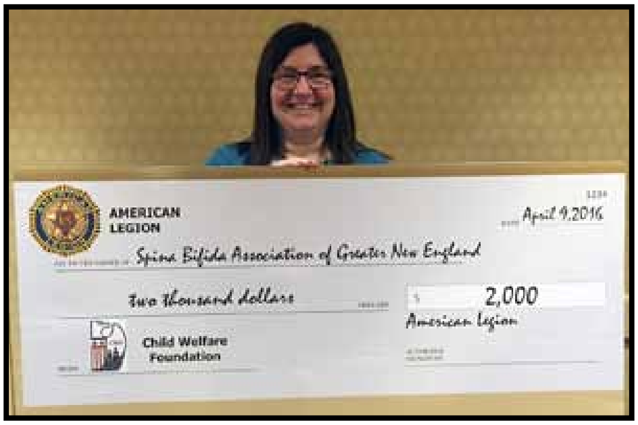
Internal Affairs: Focus on finances and human resources

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.

Thank You American Legion!



Rebecca Sherlock, Chair of the SBAGNE Board of Directors accepting a $2000 grant from the American Legion – Child Welfare Foundation. The grant was awarded to support SBAGNE outreach efforts

Living with Paralysis and Four Kids

by Bill Cawley
Manager, Peer & Family Support Program

I am the lucky and proud father of 4 awesome kids: Liza Jane 12, Lincoln Jix 11, Mary Kate 10, and Hugh Douglas, 6. I am also a C6-C7 quad after a diving accident 24 years ago down on the Jersey Shore. I use a manual wheelchair and am fortunate to have enough dexterity in my hands to live independently. My hands are pretty impaired, but I can dress myself for example.

My wife and I met and got married well after I got hurt. We started having kids right away. I think all new dads are worried about being a good parent. My situation elevated that fear to a whole new level. I knew this going in, but when you have your first child in your arms, it becomes so much more real. I wanted to be a regular dad and do all the same things others dads do. I didn't want my kids constantly saying: "no we didn't do this or that because my daddy is in a wheelchair." I didn't want them missing out on stuff because I was in a chair. I knew I would work hard to avoid them feeling that way, but I had sort of accepted that if I couldn't do something with them then it didn't count. That I wasn't a regular dad.

However, my understanding of what a regular dad is started to change when I stopped thinking about what I thought my kids wanted, and started to listen to and see what they acutally wanted from me. I started to notice when they asked me to do stuff with them.

They wanted me to read them a story. If they wanted to do a puzzle, they would grab one and, instead of doing it on the carpet, they would climb up on my lap and spread it out on the kitchen table so I could do it with them. When we went outside, they would play on the driveway instead of the grass.

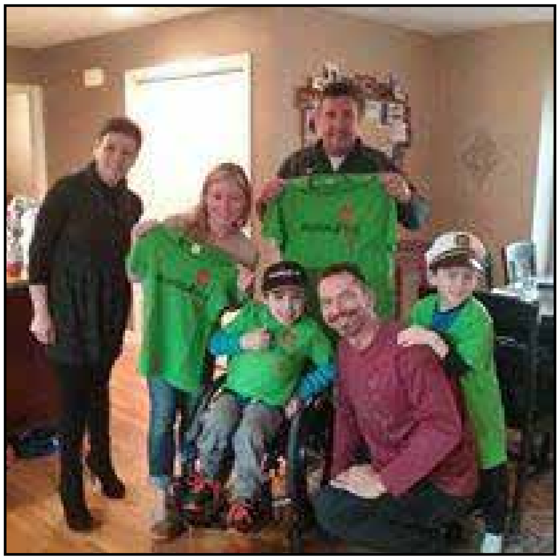
It all came together for me one day when we were at the Jersey Shore. We were at the beach and my two oldest children, who were then probably five and three years old, were building a sandcastle. In all honesty, it was just piles of wet and dry sand all mashed together. I was out in the sand but couldn't help them build it, but they didn't care. They were telling me where the drawbridge was, where the knights and princess were, about the horses and farm animals, etc. They just wanted me there to share the experience with them. It didn't matter if I built it. It only mattered that I was there to enjoy it with them.

They won't remember if you built the castle, if they sat on your shoulders at a parade, if you rolled down a hill with them at a park, or if you laid down with them when you put them to sleep. If you are there, they will remember you were at the beach, the parade, and the park and that you put them to bed. What they will remember is that you were there with them. A real dad is there, encouraging, supporting, laughing, teasing, pushing them, and comforting them whether you are in a wheelchair or not.

This blog post was originally featured on christopherreeve.org.

What is a Running Buddy?

by Amy Bois



It is someone who runs for an individual who cannot run and offers up their miles for that person. My son Tyler Bois (10) is blessed to have a running buddy, Nicola Di Silvio, from Italy who has running friends running for Tyler all over the country. The initiative is called #running4tyler & currently has over 30+ runners who offer up their miles. We had the honor of hosting Nicola & his family this past weekend as he embarked on his US running tour #running4tyler. He will be running in 9 different locations to help raise awareness for spina bifida!

In his honor, we held a BIG PIZZA PARTY to let him know how much we appreciate his support of Tyler & his dreams. We also hosted a FUN RUN the following morning at 9 a.m. at our house so that the community could all run together with Tyler & Nicola. We were so fortunate to have over 50 runners/walkers participate in this event even with it being 28 degrees. Fun was had by all!! During these 2 events we were able to raise $1,500 for SBAGNE!!

National Women's Health Week
May 8-14, 2016

National Women's Health Week is an observance led by the U.S. Department of Health and Human Services' Office on Women's Health. The goal is to empower women to make their health a priority. The week also serves as a time to help women understand what steps they can take to improve their health.

To improve your physical and mental health, you can:

Visit a doctor or nurse for a well-woman visit (checkup) and preventive screenings.
- Get active.
- Eat healthy.
- Pay attention to mental health, including getting enough sleep and managing stress.
- Avoid unhealthy behaviors, such as smoking, texting while driving, and not wearing a seatbelt or bicycle helmet.

To support National Women's Health Week, you can:
1. Support our Thunderclap through Twitter, Facebook, and/or Tumblr to get the word out to your followers and friends. Be sure to ask them to sign up for the Thunderclap, too.
2. Visit **www.womenshealth.gov/nwhw** for more ideas on how you can spread the word about the week and the importance of women's health.
3. On Monday, May 9, watch as everyone's posts are shared across the country.

Cheri Blauwet:
A story of success that started at a young age

Success requires a process that often begins with simply trying, and Cheri Blauwet is a great example of it. Cheri is a Paralympic wheelchair racer who has won several races in her day, including the 2004 Boston Marathon, and has competed at the Olympic level in Sydney, Athens and Beijing. Yet, such accomplishment wouldn't have been possible if her track high school coach hadn't encouraged her to start playing sports when she was in the eighth grade.

"The high school part of my career was extremely important because it enabled me to build the skills I needed someday to be very successful," Cheri said during an interview with BU PRLab.

According to Cheri, she first got involved with sports when she was 14 years old because she found the team to be a friendly and supportive community. "Initially, like most people, I wasn't very good at the sport, and it took many years to actually develop the talent and skill I wanted," she said.

However, with every training she completed, she began to fulfil personal goals and reach great achievements. During her senior year of high school, she attended the USP Development Camp for Sports and realized that this could be more than just a fun extra-curricular, it could also give her a competitive career.

Cheri is an excellent example of why it pays off to start playing sports at a young age. It's a period in life when you have more energy and time, and when you can easily develop and learn new skills.

"If I hadn't been out there learning every day on the track in high school, I certainly never would have made it to the Paralympics when I was in college," Cheri said. "You have to start from the ground up and you have to climb the mountain one step at a time, and during high school and middle school you have more time and less external pressures to do it."

Outside of her athletic career, Cheri graduated from college with a degree in molecular biology and later on she attended medical school. She's now a sports medicine physician and on a daily basis, she affirms that sports have great benefits, especially for youth development.

"We want our kids, even if they're not going to be superstars, to have valuable experiences in life. Sports not only enhance physical fitness and encourage a healthy lifestyle, but also help to build self-esteem," said Cheri.

For Cheri, sports have been an outlet to develop her personality, belong to a community, be active, healthy and have fun. As Cheri mentioned during her interview, "all of those things are so important and we don't want kids with disabilities to be isolated and to not have those opportunities, they at least need to give it a shot."

Kids with disabilities can take advantage of events at The Paralympic Experience – a great opportunity for youth to dip their toes into the world of adaptive sports.

If you live in the Greater Boston area and you have a physical disability or a visual impairment, we'd love to meet you Paralympic Sport Club Boston (PSC Boston) brings together youth who have physical or visual impairments to learn, practice and compete in a variety of sports including track & field, swimming, tennis, and cross country skiing. PSC Boston seeks to increase participation in Paralympic –style sports and supports athletes at all levels of skill and competitiveness with expert coaching, camaraderie and shared ideas among Paralympic sport mentors, protégés and peers.

PSC Boston facilitates and supports athlete inclusion on school-based and community-based teams/clubs/programs while fostering personal growth, skill development, and age-appropriate play among teammates with and without disabilities. PSC Boston programs are aligned with existing and anticipated opportunities in YMCA, MIAA, and ECAC competition, as well as with sports contested at the Paralympic Games. PSC Boston supports collaborating school and community programs with inclusion planning, coach consultation, and identification or development of appropriate competition.

For more information visit **www.adaptivesportsne.org**

Originally published by Adaptive Sports New England on **www.adaptivesportsne.org**. Reporting by BU PRLab.

Welcome to amazonsmile

You shop. Amazon gives.

We would to remind everyone that we are now active with Amazon Smile. This means that Amazon will donate 0.5% of the price of your eligible AmazonSmile purchases to the Spina Bifida Association of Greater New England whenever you shop on AmazonSmile.

To do this go to: **https://smile.amazon.com/ch/23-7305430**

We also have a click-to option on our website page.

Self-defense Class Offerings

SBAGNE is collaborating with IMPACT to provide self-defense classes for middle and high school students. Training will be two 4 hour sessions, co-ed and for youth of all abilities.

IMPACT Boston is a Member Program of IMPACT ® International. IMPACT programs across the country and international share a commitment to teaching verbal and physical safety skills as part of a broad movement to prevent sexual assault and other types of violence.

For more information about IMPACT visit **www.impactboston.com**.

Please contact Ellen at **edugan@SBAGreaterNE.org** for more information regarding dates/times.

Clinics

Boston Children's Hospital
Boston, Mass
Spina Bifida and Spinal Cord Conditions Center
(617) 355-8532
www.childrenshospital.org

Shriner's Hospital
Springfield, Mass
Orthopedics/Spina Bifida
(413) 735-1234 or (800) 322-5905
www.shrinershospitalforchildren.org

Dartmouth Hitchcock Children's Hospital at Dartmouth
Lebanon, NH (DHMC)
Spina Bifida Clinic
(603) 653-9883
www.dartmouth-hitchock.org

University of Vermont Medical Center Spina Bifida Collaborative Care Program Children's Specialty
Burlington, VT 05401
(802) 847-8840
www.uvmhealth.org

Maine Medical Partners
Spina Bifida Program
Portland, ME 04102
(207) 662-5522 or (866) 860-6277
www.mmc.org

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Milford, MA 01757

Parents Helping Parents
Cara Packard
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Youth & Adults Group
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Walk-n-Roll
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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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Web site: **www.SBAGreaterNE.org**

CHANGE SERVICE REQUESTED

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