Summer 2016

SBAGNE
news

TEAM VICTORIA ROSE WALK-N-ROLL FOR SPINA BIFIDA

SBAGNE
news

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Upcoming Events

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

Laura Lambert New SBAGNE Operations Associate

Our longtime Operations Associate Jeffry Vendetti is now nearing the end of his time at the Bryant University Graduate School. Sadly, this also means that Jeffry is also nearing the end of his time at SBAGNE.

However, this also means we get to introduce to you our new Operations Associate Laura Lambert! Below is some information on SBAGNE's newest addition.

Laura Lambert recently returned from working on a research project in Lesotho, southern Africa, studying the prevalence of teenage motherhood in the region. She has a Master's degree in Visual Anthropology and a background in documentary film and social research. Laura is excited to expand her community-based work by joining SBAGNE's team as Operational Associate.

Letter from the Executive Director

In June I was able to attend the biennial SBA National Conference in Minnesota. More than 750 individuals living with Spina Bifida, families, health care providers, chapter leaders and vendors attended. I have attended several conferences during my tenure with SBAGNE and always come back to Massachusetts energized and with numerous ideas to enhance chapter activities. Topics this year included bowel/bladder manangement, aging with Spina Bifida, learning issues and developing a social network. SBAGNE provided four awards to individuals and families to attend the conference. The next conference is expected to be in 2018. Location to be announced later this year!

SBAGNE has had a busy summer – kayaking with Waypoint Adventures and summer picnics in Canton, Mass and Gray, Maine. The weather was perfect, though a bit warm! These events continue to provide the opportunity for folks to connect with old friends and make some new connections. Social networks and connections are vitally important for all of us. SBAGNE is pleased to provide these opportunities which we consider a vital part of the SBAGNE mission. Visit www.SBAGreaterNE.org for information on upcoming activities.

SBAGNE continues active on Facebook and twitter. If you haven't done so, please "like" us. There are daily posts regarding SBAGNE activities as well as those of other organizations. Another way to stay connected to the SBAGNE community.

On August 21st, TEAM SBAGNE will once again be running in the **Falmouth Road Race**. If you are in the area, come and cheer TEAM SBAGNE on as they run to raise awareness and funds to support the organization. New in 2016, SBAGNE will be participating in the **Tour de South Shore** in Hingham, Mass. Thanks to the McCourt Foundation and the efforts of the Holleran Family, SBAGNE has 20 openings for those interested in riding, 20 or 50 miles to support SBAGNE. Walkers are welcome to join the 5K. Join us to support Team Liam's Lead Outs.

Enjoy the remainder of the summer. Stay cool and hope to see you at an SBAGNE event soon.

Ellen

Ellen Dugan, Executive Director, SBAGNE

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

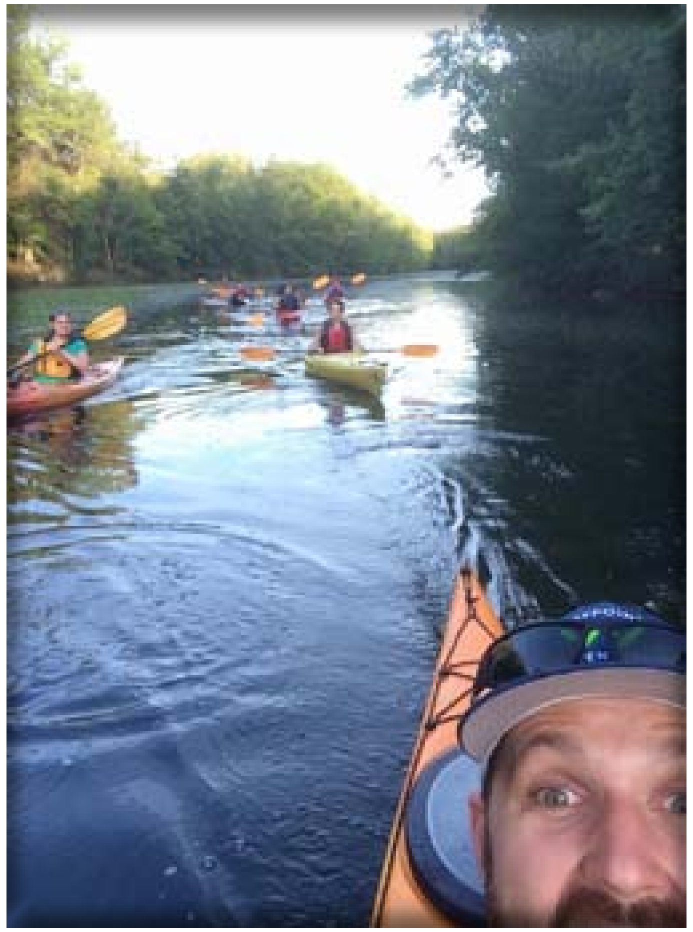
Contact Ellen at edugan@SBAGreaterNE.org if you are interested or would like more information.

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

Waypoint Adventures Kayaking!

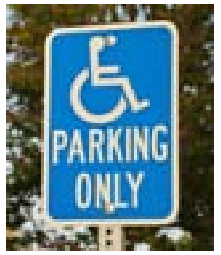


FUN NIGHT KAYAKING WITH WAYPOINT ADVENTURES: The crew kayaked on the Upper Mystic River – beautiful site and relaxing evening.

Outreach Mailing

This summer SBAGNE has completed a mailing to 200 New England family practioners, ob/gyns and pediatricians. Our goal is to spread the word about SBAGNE and reach greater numbers of those in the Spina Bifida community. SBAGNE will continue outreach efforts. You can assist SBAGNE in this effort. If you would like a packet of information to share with your physicians, please let us know. We would be happy to provide information. Our objective is to expand our community and reach all those in living with the Spina Bifida in greater New England.

Reporting Disability Placard Abuse



Some of the most common forms of placard abuse are:

- Parking in a handicap spot without a placard or handicap plate
- Using someone else's disability placard or handicap plate
- Using an expired placard
- Using a placard or plate that was issued on based on incorrect or outdated information
- Making a counterfeit placard or altering an existing one

If you see someone abusing a disability placard you can call your local polic department or fill out an online form at the RMV, **http://www.massrmv.com/rmv/hp_complaint/**

McCourt Foundation - Tour de South Shore

Join Team "Liam's Lead Outs" for a 20 or 50 mile ride around the South Shore on October 1st. Usher in Spina Bifida Awareness Month, raise awareness and support SBAGNE. Visit **www.SBAGreaterNE.org** for more information.

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**.

THE University of Vermont MEDICAL CENTER

UVM Medical Center in Burlington, Vermont is excited to announce their Family Centered, Multidisciplinary Spina Bifida Collaborative Care Program (SBCCP) is up and running. Starting in September 2015, this monthly clinic offers pediatric services in Nephrology, Urology, Neurosurgery, Physiatry, Orthopedics, and Developmental pediatrics. The clinic was specifically designed with input from their Patient and Family Advisor to promote patient and family centered care. The clinic is funded by the Children's Miracle Network.

For more information please go to the SBCCP website by searching "UVM Spina Bifida" or: **https://www.uvmhealth.org/medcenter/Pages/Departments-and-Programs/Spina-Bifida.aspx**

SBAGNE relies 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 Possibility - $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.

Welcome to amazonsmile

You shop. Amazon gives.

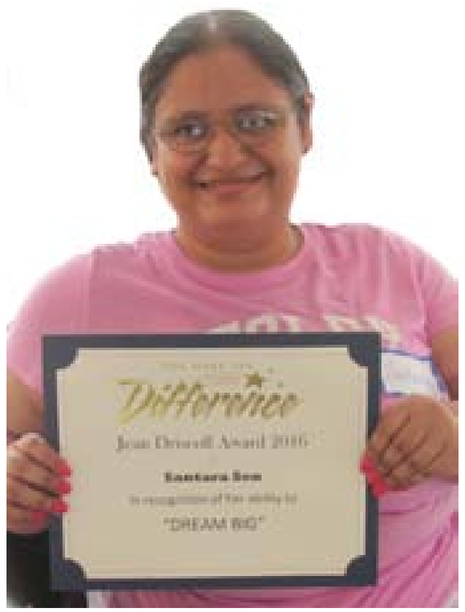
We would like to remind you that we are now active with Amazon Smile. This means that Amazon will donate 0.5% of the price of your eligible AmazonSmile purchases to the Spina Bifida Association of Greater New England whenever you shop on AmazonSmile.

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

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

Jean Driscoll
“Dream Big” Awardee

by Santara Sen



When I realized I had to write a personal statement about why I think I should receive the Jean Driscoll Award, at first I was very nervous about it. As I thought about Jean’s accomplishments and compared them to mine, it seemed like there was no comparison between us. Growing up and living with Spina Bifida has definitely has had its ups and downs. I have encountered many challenges and obstacles medically, in school both socially and academically, and within my family life. In this statement, I will be discussing those challenges and their impact on my life and how I have been able to overcome them to achieve my current goals.

From a culture/family perspective, growing up with Spina Bifida in an Indian family was and still continues to be very challenging. The concept of “disability” is extremely foreign in India, given the lack of medical care and access to assistance/services such as personal care attendants (hereafter referred to as PCAs), home nursing, adapted cars and so forth. My family, being new to the U.S. when I was born, did not have access to the supports they needed to help me as a young child and to a certain extent, believed the negative stereotypes they were told by the doctors who delivered me. (Basically, they were told I would be bedridden all my life and not to expect me to accomplish anything.) As a result, it took me much longer to prove that I can be just as capable and independent as others in the family. Even to this day, I am not sure if all my family members accept me as I am.

I recall in school, the expectations of my teachers vs. that of my family were vastly different and as a result I sat through many “interesting” IEP meetings. My teachers set certain goals/achievements for me, while my family had other ideas of what I should do. Because of these cultural conflicts and my family’s grim view of my life, it took me much longer to learn many basic concepts and skills, but I have mastered them nonetheless and am achieving more every day. For instance, I have utilized the assistance of PCAs since I was a teenager who help me maintain my independence and well-being, which ultimately allows me to pursue all my goals in life. I also utilize the MBTA’s para-transit service, The Ride to access these opportunities as well and it helps me be active in the community. Despite reliability issues with both services, I have been able to do many more tasks and achieve goals independently.

From a medical standpoint, in many ways I have been extremely lucky. During my young life, I did not have nearly as many surgeries as a “typical” child with Spina Bifida. Fortunately, all of my corrective surgeries occurred within the first ten years of my life and then they subsided. However, frequent doctor’s appointments and my corrective surgeries affected school in many ways. It resulted in attendance issues which made it extremely difficult to keep up with the curriculum, which was frustrating and overwhelming at times. Medical hurtles, as well as my complicated family dynamic throughout the years ahead, had a negative impact on my school performance, which was not always understood by my teachers. In high school, I recall often being told many disparaging views about my future. In a nutshell, my teachers said that I would never accomplish or amount to anything and I would be dependent on my family my whole life. I still live in the same town and many of those people are still there and have the same perception of me, even though so much has changed since high school graduation in 2002. In the last few years, I have seen some of those same teachers in the community and one of the first things they will say is “So…you’re still living at home, huh?” which, while it’s true at the moment, is really annoying because it completely overshadows the many things I have accomplished since high school graduation, almost fifteen years ago.

There have been many others over the years who have shared that same perception of me, and were not at all hesitant to tell me right to my face or right in front of me (to others), exactly what they think about my dreams and ambitions. However, I do my best to ignore them and continue working on my goals. It has often been challenging and definitely had an impact on my self-esteem, but if I let every single one of those comments get to me, I truly wouldn’t wake up in the morning and face each day. I actually find great joy and pride in accomplishing the things people said would never happen. Although people are entitled to their opinion, I truly believe you should not let that impact what you want to achieve in your life. Even though it is taking time and I have not yet accomplished everything I want in life, I still keep going because I know it will be worth it in the end.

I also struggled through many of the academic and social challenges that people who have Spina Bifida often face. With regards to academics, I struggled with math, reading, (standardized) testing as well as many executive functioning skills and had to work through those challenges. Socially, I struggled as a kid because it seemed like I was always perceived as “the girl in the wheelchair” as it was often difficult for other children and teens to comprehend my challenges. As a result, growing up I did not have a lot of friends and even dealt with the emotional burden of being made fun of and/or bullied. Because of this, I am a shy and reserved person, especially in large crowds, which still gets misunderstood sometimes as “standoffish” or “rude”. In both high school and my early years of college as an undergrad, I struggled to figure out where I fit in because of “cliques”. For years, it seemed like I didn’t belong in any of the social circles around me. However, despite all of that, I have managed to keep a small circle of very close friends who have been there for me through the thick and thin. I am also happy to now be part of the SBAGNE community and to be able to connect with other people who have Spina Bifida. It has been great getting to know the children and their families and to interact with them, and to get to know other adults who have had similar challenges as me and to be able to learn from them.

Currently, I am a graduate student in the Master’s program at Lesley University studying Early Childhood Education, and I have been doing very well despite several obstacles along the way. One of those challenges is not having the benefit of obtaining the Bachelor’s degree in Education. Because of this, I felt very overwhelmed, especially in the beginning while learning what others who have a degree in Education already know/have experience with. Many of them have been teaching for some time, whereas I have been learning as I go. Moreover is the added challenge of learning how to make physical accommodations in my (future) classroom and make it functional for me so I can meet all the children’s needs. Luckily, the faculty and staff at Lesley have been extremely supportive in helping me work through these issues.

The second challenge I encountered was that when I first started the program, I was still dealing with post-surgical complications from my second lymphedema surgery that persisted for over a year in total. As a result, during my first few months of school, I had to juggle multiple wound care and rehab appointments while taking classes, doing field work etc. It was definitely problematic trying to figure out how to schedule in all of these appointments in between everything else. However, I managed to get it all done and am now approaching the end of the program, despite all these bumps along the road.

The final and in my opinion, the biggest challenge I have encountered during my education at Lesley is related to finding and maintaining a reliable PCA. Due to medical challenges related to my disability, I utilize the assistance of PCAs for day to day assistance with various tasks. Over the years, particularly in the last five years, I have had several difficulties in finding and maintaining reliable workers, as they often do not understand the significance of their role in my life. Without a PCA who shows up and performs their job on a consistent basis, it is a struggle to maintain a good quality of life. The frequent rehiring process is often very time-consuming and overwhelming because it becomes the main focus in my life, overshadowing everything else at the time. Still, I have done my best to continue pushing forward despite all of these issues.

Becoming a teacher has been a goal of mine ever since I was a kid. For many years, I could not picture myself doing anything else. I have always loved working with children, both in and out of the classroom setting, and I hope I can make a difference and be a positive influence in their lives. I especially want to teach young children because they are so energetic, enthusiastic, and genuinely want to learn about the world around them. I want them to know that with a positive attitude, hard work, and dedication that they can achieve anything. In addition to teaching children reading, writing, and math, I also want to teach them complex concepts such as acceptance, tolerance, and respecting and appreciating differences in people. As a (future) teacher, one of my goals is to include a disability awareness unit in my curriculum and I am already brainstorming different ideas to accomplish it in developmentally appropriate ways. I have ideas on hands-on activities where the children can try to emulate different disabilities, resources for children’s literature featuring characters with disabilities, and want to include different speakers (with a given disability) that the children can learn from by asking them questions about their everyday lives. Lastly, I want to hold frequent open discussions regarding what the children are thinking/learning/feeling from all of the activities presented to them. My hope is that they will learn from the experience that people with disabilities are just like everyone else and should be treated with the same respect. I think it is important to start teaching these concepts at a young age so it stays with them as they get older. I am very excited to be so close to finally achieving this goal after struggling for years facing many challenges along the way.

In conclusion, despite the challenges of living with Spina Bifida, I have accomplished many great things, and still continue to strive for all of my goals. Making such progress towards my educational goals has been amazing and I hope to enter my career soon. I have also enjoyed being involved in many different organizations, both past and present, as they have all been positive in some way. Lastly, I enjoy spending time with my friends, going out to dinner or the movies and just having fun. Some of my goals are still a work in progress, but I finally feel like I am getting somewhere. I am very fortunate now to be surrounded by many supportive and encouraging people who genuinely care about me. I believe that having a supportive network makes all the difference in the world. The most important thing is that, despite all the difficulties and sometimes feeling discouraged and frustrated by setbacks, I still continue to pursue these dreams.

WALK-N-ROLL FOR SB

Thank You!

We just wanted to say a big ‘Thank You!’ to everyone that attended our Walk-N-Roll this past June. Your presence certainly made this event fun and helped this community continue to grow. We also appreciate the fundraising efforts from each individual and each team.

The top 3 teams included:
- Gagnon Gang- $6,453
- Will’s Walking Wonders-$5,283
- Hi Fives 4 Helena- $4,167.33

Our top 3 individual pages included:
- Emily Gagnon- $6,403
- Kathleen Gustafson- $5,208
- Yvette Anger- $2,878

We would also like to thank our WNR Superstars. who were individuals that raised $500 or more for Walk-N-Roll Canton.

Super Stars:
- Emily Gagnon
- Yvette Anger
- Katy Hannan
- Helena Fontaine
- Cambry Cutter
- Jack Paynich
- Linda Long Bellil
- Sara Fontaine
- Victoria Sousa
- Nicole Daly
- Sam Goldman

Another special ‘Thank You!’ to our sponsors for this event as well:

Silver Sponsor:
Hollister

Bronze Sponsors:
180 Medical
Coloplast

Friends of SBAGNE:
Wilmington Medical
Bryram Health Care

We would like to finish by saying that all teams and individuals helped make this event fun and successful. Thank you all for your continued support that has helped make events like these what they are today.

Hollister

180° MEDICAL

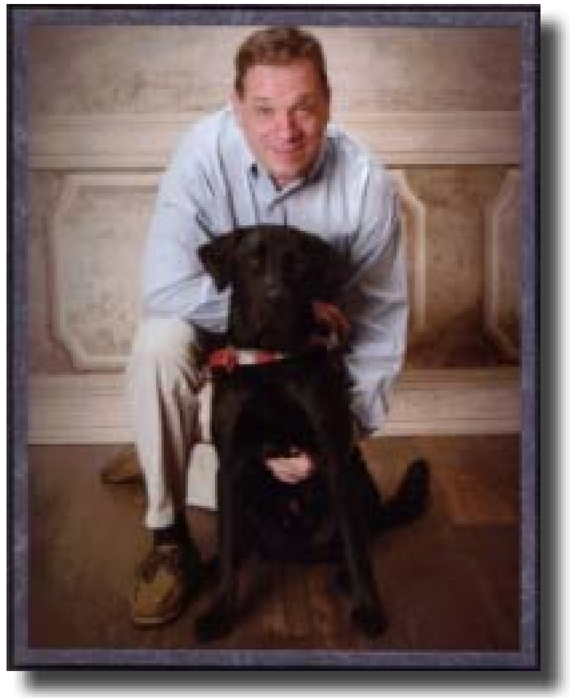
Coloplast

WMS

Byram Healthcare

FAQS about Service Animals

by Carl Richardson



As a person who has used a service animal for just over 15 years, I can tell you I get stopped constantly and asked a lot of questions. I once even got stopped by Bill Gates of Microsoft; he asked me if my guide dog was a bomb sniffing dog.

Below are answers to some of the most common questions I get asked.

- People with disabilities who use guide or service dogs can go everywhere.
- A service animal is a dog that is individually trained to do work or perform tasks for a person with a disability.
- Examples of Service Animal include those who guide people who are blind, alert those who are deaf, pull a wheelchair, alert an individual to a seizure attack, remind one with a mental illness to take his/her medication, and much more.
- A service animal is not a pet.
- Do not touch the animal or give him/her treats without the permission of the owner.
- Service animals are not required to be certified. If the person tells you it is a service animal, treat it as such.
- A person is not required to carry proof of disability or to say why he/she requires the use of a service animal.
- A service animal must be on a leash if local ordinances require that. But a harness, special costume or muzzle are not required and are only present when needed for the animal to do its job.
- If the animal is out of control or presents an active threat the handler may be required to remove it from the site.
- A business is not required to walk or otherwise care for the animal.
- If an individual asks that you hold a guide dog, and if it is appropriate to the situation, hold the leash not the harness.
- Allergies and fear of dogs are not valid reasons for denying access or refusing service to people using service animals.
- An Emotional Support Animal is not a Service Animal.
- A Service Animal cannot tell when a traffic signal changes color.
- A Service Animal does not always know where it is. It is up to the handler to know where he/she is at all times.According to the Americans with Disabilities Act, (ADA), a service animal can only be a dog.
- A business or service cannot charge a customer extra for having a service animal.
- My service animal is still smart even if he doesn't know how to give "paw".
- Yes, my dog likes to play fetch.

The next time you see a service animal, remember these answers and tips. Also, remember to ask the handler what you can and should do, and ask yourself how you would like to be treated if you had a service animal.

Permission to reprint granted by INDEX (Information for People With Disabilities, Their Friends, Families and the People Who Serve Them).

Disability Etiquette

Do awkward situations sometimes arise? Here are some tips you can share with folks. Add your own!

by Elizabeth Brodeur, SBAGNE Administrative Intern

Things to Avoid

- Pity or feel sorry for people who have disabilities or use wheelchairs.
- Wheelchairs are empowering and allow people with disabilities to get around where they wouldn't otherwise be as free...often they can move faster than people who walk!
- Put people with disabilities "up on a pedestal."
- They aren't "superheroes," "brave," "courageous," or "inspiring;" rather, people with disabilities just want to do the same things that anyone without a disability wants to do.
- Pat them on the head. It is patronizing and not respectful.
- Assume someone who is deaf can read lips. Lip reading is very uncommon.
- Pet a service animal who is at work. Ask if it is OK with their owner.
- Touch their wheelchair, scooter or cane. People with disabilities consider their equipment part of their personal space.
- Make assumptions. People with disabilities are the best judge of what they can or cannot do. Don't make decisions for them about participating in any activity.
- Do not exclude people because of a presumption about their limitations.

Things to Do

- Use "people first" language
- Respect that people with disabilities aren't defined by their disability, they are people first, disability second ("OUT" terms: "handicapped," "the disabled," "wheelchair-bound," "confined to a wheelchair." "IN" terms: "people with disabilities"; "a person who uses a wheelchair"; "person with Autism"
- Ask and don't assume someone needs or wants help even if they appear to be struggling with mobility.
- Think of a wheelchair or other mobility aide as a part of the user's personal space. Don't lean on it, push it without asking, put your feet upon it, etc.
- Speak directly to people with disabilities and with age appropriate language not to the people who may be accompanying/assisting them.
- Bend down or pull up a chair to speak to someone in a wheelchair at their eye level. It is less stressful on their neck and more respectful.
- Be sensitive about physical contact. Some people with disabilities depend on their arms for balance. Grabbing them, even if your intention is to assist, could knock them off balance.
- Avoid outdated terms like "handicapped", "crippled", or "retarded."
- Be aware that many people with disabilities dislike jargony, euphemistic terms like "physically challenged" and "differently abled." Say "person who uses a wheelchair" rather than "confined to a wheelchair" or "wheelchair bound." The wheelchair is what enables the person to get around and participate in society; it's liberating, not confining.
- Avoid negative, disempowering words "victim"or "sufferer."

Summer Gatherings

On July 23rd in Canton, Mass and July 30th in Gray, Maine, SBAGNE held the annual summer picnics. The weather was perfect for both, although a bit muggy in Canton. The 40 folks who attended Canton had a chance to cool off in the pool, have lunch with friends, say 'Hi' to Slyde (NE Revolution mascot) and ended the day with a pontoon boat ride. 50 SBAGNE constituents from various parts of Maine traveled to the Maine Wildlife Park. There was enough time to socialize, have lunch and then visit with and feed the animals housed at the park.

As with other SBAGNE gatherings, the summer events offer an opportunity for renewing friendships and building a network of support. Supporting these connections is the focus of SBAGNE get-togethers. By this measure – both were a great success.

CrossFit

by Arika Zielfelder

My name is Arika Zielfelder. I am 25 years old and use a manual wheelchair, due to having Spina Bifida. I have been involved in CrossFit for a year and a half now, at a local CrossFit gym (also referred to as a "Box"), called EverProven CrossFit. My entire life I have always been active and participated in many different sports. Over the years I have tried going to other local gyms in order to stay active on a regular basis, but always struggled finding a gym that I could use more than a couple of the pieces of equipment. Due to most gyms being focused on able-bodied people, the equipment in most gyms is focused on legs and lower body, so I never felt like I was getting a complete overall body workout.

I had heard of CrossFit, but had no idea what it was. I wanted to learn more, so I did an internet search for CrossFit locations near my house, and EverProven CrossFit's information was the first result I found. I called them and scheduled a meeting with one of their coaches, Kate, to learn more about it and see if it would be something that could work for me. I was so excited to find out during the meeting that CrossFit is designed to be modified for anybody, of any ability! The idea of CrossFit is to apply what you learn in the gym, and the strength and fitness that you gain, to your everyday life. It was exactly what I had been looking for!

I have gained and learned so much over the last year and a half since joining EverProven CrossFit! Not just in strength and overall fitness, which has been huge, but also in the support and encouragement that is provided through this community. The coaches, staff, and other members have been so supportive and willing to help me learn and adapt, so that I can accomplish any and all goals that I have; as well as helping me set and reach goals I may not have thought were possible! I am able to participate in the group workout classes, with all of the other athletes, my wheelchair doesn't hold me back at all (I just have to make slight modifications to the workouts, sometimes). There are resources and groups out there that specifically focus on adaptive CrossFit athletes, which in combination with the coaches from my gym, have been extremely helpful. A couple of the available resources are WheelWOD, and I Am Adaptive.

Some of the skills and strength I have gained through my CrossFit workouts are; being able to sit independently on the floor without any support (which I have applied to my everyday routine of sitting on the floor to groom my Service Dog), I am now also able to walk longer distances on my crutches, and can stand without any support. I also currently have the goal of wanting to walk a few steps without any type of assistance, which I am beginning to reach. Since starting CrossFit, a lot of back pain I had been experiencing has been greatly reduced, due to being able to work on the strength of my entire body. Gaining these skills has allowed me to participate in everyday activities outside of the gym, which may not necessarily be accessible or as easy to do if I only relied on my wheelchair. A huge accomplishment I recently made was competing in the WheelWOD CrossFit Championships in Ontario, Canada. This is the first time that this event had ever been held, and it was a competition for adaptive CrossFit Athletes from all over the world to compete against one another. I am proud to say I placed third overall in the women's division of the WheelWOD Championship.

Road to Rio - 2016 Paralympics September 7-18
Tatayna McFadden – Paralympic Wheelchair Racer

Check your local tv listings for Paralympic air times

Becoming an Athlete with a Disability

The transition was difficult and Tatyana's health worsened so she was enrolled into various sports groups in hopes that it would build her strength. It did, and then some, and so began Tatyana's extraordinary life as an athlete. Tatyana tried every sport she could find; wheelchair basketball, swimming, ice hockey, and even scuba diving. From the start she fell in love with wheelchair racing –a sport through which her powerful arms immediately brought success.

The Start of the Paralympics Medal Count

At 15, Tatyana made her Paralympic debut in Athens in 2004. She was the youngest member of Team USA. She returned from Greece with her first two medals and a hunger to become the best. Two years later she was, winning gold at the World Championships and setting a new World Record in the 100 meter event.

At the 2008 Paralympic in Beijing, at 19 and still in the infancy of her athletic career, she earned four more medals. In London, in 2012, she added another four medals, three of which were gold. One year later, at the 2013 World Championships, she became the first athlete in history to win six gold medals at the same competition. Her dominance was in full swing and she was still only 24.

Tatyana and Her Wheelchair Hit the Marathons

Tatyana challenged herself with the professional marathon circuit in 2009, and with her win at the Chicago Marathon, she set off an extraordinary string of first place finishes that is still going strong. In 2013 she won the Chicago, London, Chicago and New York marathons, becoming the first man or woman, able-bodied or disabled, to win the Grand Slam (4 World Major Marathons in the same year) and then repeated her Grand Slam victory in 2014. In 2015, Tatyana has already won both London and Boston and is poised to win the Grand Slam for a third year in a row.

Always looking for a new challenge, and intrigued by the idea of returning to Russia to race, in 2013 Tatyana decided to give cross country ski racing a try in hopes of earning a spot on the Sochi Paralympic Team. With less than a year of on snow experience in her life, Tatyana made her winter Paralympic debut in Sochi and in a dramatic sprint to the finish line she narrowly missed yet another gold medal, settling for silver. It was first of what promises to be many more winter medals for Tatyana and the 11th Paralympic medal of her career.

In 2014 Tatyana graduated from the University of Illinois with a degree in Human Development and Family Studies and is returning to U. of I. to pursue graduate work in Education. When she isn't racing or studying, she works as a national advocate for equal access for people with disabilities, is a lifetime member of the Girls Scouts, is on the Board of Directors of Spina Bifida of Illinois and speaks to children and adults about healthy living.

Fighting for the Rights of People with Disabilities

McFadden had difficulty competing at high school. Atholton High School would not allow her to race at the same time as able-bodied runners, with officials saying her racing chair created a safety hazard and gave her an unfair advantage (as the best wheelchair racers are noticeably faster than runners over long distances). She could compete in separate wheelchair events at high school meets, which meant that she would circle around an otherwise empty track by herself, which embarrassed her.

In 2005 Tatyana and Deborah McFadden filed suit against the Howard County Public School System and won the right for her to race with her fellow classmates, with U. S. District Court Judge Andre Davis stating "She's not suing for blue ribbons, gold ribbons or money — she just wants to be out there when everyone else is out there."

McFadden's lawsuit is credited for the eventual passage of the Maryland Fitness and Athletics Equity for Students with Disabilities Act, requiring schools to give students with disabilities the opportunity to compete in interscholastic athletics.

Tatyana went on to press for federal legislation so that other students with disabilities across the USA would have equal access. In 2013 it was passed and now all students with disabilities will have opportunities to be involved with sports in school.

She was also a leader of an ultimately unsuccessful effort against a 2012 Russian law to prohibit adoptions of Russian children by American parents.

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Reprinted from http://tatyanamcfadden.com/about-tatyana/

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