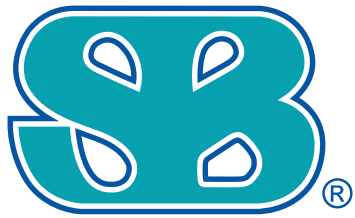


Winter 2016



SBAGNE

news



Holiday Party Fun!



Inside this Issue

- Walk-n-Roll and Falmouth Road Race events kick off!
- Jean Driscoll Dream Big Award Announcement
- Wintertime Fun Sport Options

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Events

Adult Get Together: Museum of Science (MOS)

Saturday, February 27th, 1:00-4:00 PM

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

Watch "Wild Africa" IMAX Film at the MOS (3 PM) approximately 50 minutes. SBAGNE will purchase tickets to the IMAX film with an RSVP by February 22, 2016.

RSVP no later than Monday February 22, 2016 online, by e-mail to edugan@SBAGreaterNE.org or call 888-479-1900.

BLIN'G 2016

Friday, March 4th - Sunday, March 6th

BLIN'G is for young women, living with Spina Bifida, ages 12 -17

Registration now available at SBAGreaterNE.org.

Questions? Contact Ellen Dugan at edugan@SBAGreaterNE.org

Regional Education Days

SBAGNE will be hosting 2 Education Days, across the service area, in March 2016. It is hoped that the 2 Education Days will give increased numbers of individuals and families the opportunity to participate. Watch your mail and visit SBAGreaterNE.org to register today.

Saturday, March 19th – Freeport, Maine

Saturday, March 26th – Springfield, Massachusetts



SBA National Conference, Minneapolis, Minnesota



SBA of Greater New England will be awarding Conference Scholarships. Additional information is available at SBAGreaterNE.org.

Letter from the Executive Director

Happy New Year! I hope each of you and your families had a wonderful holiday season. The annual Holiday parties in Massachusetts and Maine were well attended, with everyone enjoying good food; connections and a visit from the “Jolly Old Elf”. Pictures are available on the SBAGNE Website.

As we move into 2016, the staff and Board are actively planning for the upcoming year. 6th Annual BLIN’G is planned for March 4-6th. TEAM SBAGNE has received 25 charity entries For the Falmouth Road race, through the Non-Profit Numbers Program. SBAGNE has been fortunate to participate in the event for more than 10 years, with many of the same runners! If you or someone you know is interested in running Falmouth, check out the note to the right for details. We are hoping to raise \$45,000 in 2016.

The SBA National Conference is planned for June 25- June 28th in Bloomington, Minnesota. The conference features not only the education sessions but is also home to SBA’s Kids! Camp. SBAGNE offers a limited number of conference awards to assist in defraying the cost of attendance. Applications can be downloaded at SBAGreaterNE.org the deadline is April 8th. Think learning experience, new friends and the Mall of America!

Best wishes for a Happy and Healthy New Year – with much LESS snow than the winter of 2015!

Ellen

Ellen Dugan, Executive Director, SBAGNE

2015 Holiday Parties

SBAGNE held two holiday parties this year: one in Massachusetts and the other in Maine. Both parties where fun, and ensured we kept our members and community close. We would like to thank everyone that went as we enjoyed a day filled with food, presents, Santa and games. These parties were a way for us at the Spina Bifida Association of Greater New England to show how appreciative we are of our constituents, and their support.

Walk-n-Roll 2016 Preparations Underway

This year, the 7th Annual Walk-n-Roll will be held at the Massachusetts Hospital School in Canton, MA on **Saturday, June 4th**. Visit SBAGreaterNE.org for the more information and a link to register your team today!



Sunday - August 21, 2016

It’s hard to believe with all the snow on the ground, that we’re just a few months away from the once again participating in the new balance Falmouth Road Race!

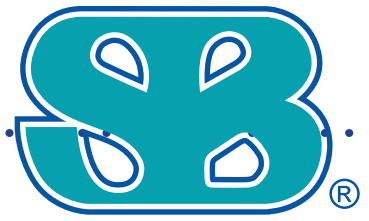
SBAGNE is once again fortunate to receive 25 entries for the Numbers for Non-Profits Program through the Falmouth Road Race. Team SBAGNE participants raise funds and awareness for SBA of Greater New England. In 2015 Team SBAGNE raised over \$40,000 to support programs and services. In 2016 we hope to raise \$45,000. Minimum fundraising amount is \$750.

Are you a runner or do you know someone who would like to participate in the Falmouth Road Race and support SBAGNE? If you are interested, contact Jeff at jvendetti@SBAGreaterNE.org. Also, watch for the SBAGNE Falmouth Road Race registration site announcement soon.

Yahoo ListSers

For many years SBAGNE has hosted an adult and a parents’ listserv on Yahoo Groups. As we have moved to Facebook, Twitter and regular communication via e-mail, these sites have been shutdown. Please like SBA Greater New England on Facebook, join us on [twitter @SBAGreaterNE](https://twitter.com/SBAGreaterNE) and keep an eye out for the monthly updates via e-mail.

In the News



Jean Driscoll “Dream Big” Award Applications now being accepted

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

by Shannon Cutter

My interest and connection to SBAGNE are in direct relation to my 10 year old daughter who has spina bifida.

In an effort to help SBAGNE provide resources, prevention and awareness I joined the Board of Directors. I have enjoyed working with the team on the Board of Directors to provide community support.

As our daughter was growing, we wanted to meet families on a similar journey as ours. SBAGNE has helped bridge many connections for our family and others through many different opportunities. It has been a wonderful and positive experience for our entire family.

Wintertime Fun Sport Options

by Bob Vogel - Newmobility.com

Winter is here and Mother Nature is covering colder climes in her annual blanket of snow. With the right adaptive equipment mounted on skis, her blanket of snow becomes a vast access ramp that enables thrills, high speeds and the freedom to venture deep into the wilderness. Here is a look at options to get your share of winter stoke.

Adaptive Skiing

“Adaptive Alpine skiing offers a freedom and exhilaration that is hard to find in any other sport,” says Bill Bowness, 57, the technical director and staff trainer at Disabled Sports USA at Alpine Meadows ski resort near Truckee, Calif. He’s been teaching adaptive skiing for 25 years, is the first disabled member of the Professional Ski Instructors of America’s Alpine demonstration team and is now in his 38th year as a T12 para. “Snow skis and adaptive ski rigs keep getting better, which makes skiing easier,” he says. “And more adaptive programs are offering a variety of high-end mono-skis in their teaching programs, partly for performance but also so students have the opportunity to try a ski before they decide to buy.”

Until recently there were two main types of adaptive skis: bi-ski and mono-ski. A bi-ski is a molded bucket seat mounted onto a frame attached to two articulating skis and is for people with limited movement. Just moving your head can help turn a bi-ski, and a stand-up skier holding tethers made of Climb-Spec webbing helps you turn and control your speed. However, bi-skis don’t have suspension and you’ll need a helper to load it onto the chairlift. Wheelers with more muscle control usually use a mono-ski — a molded bucket mounted on a suspension system that in turn is mounted onto a standard snow ski. Intermediate mono-skiers are able to ski and load onto lifts independently, and experts shred all aspects of the mountains at the same level as non-disabled skiers.

“Over the past three years a new ski called the HOC2 Glide has come on the market, and it bridges the gap between the mono-ski and bi-ski,” says Bowness. “It combines the easy balance of a bi-ski with the skiability of a mono-ski, has suspension and is self-loading for chairlifts. It’s a great option for a low quad or high-level para or a less athletic adaptive skier who wants to ski independently. If the skier’s ability improves, it converts to a mono-ski.”

When asked where potential adaptive skiers can go, Bowness says check out your local ski area. “Although it is important to call ahead and check about adaptive lessons and equipment, if a ski area has a ski school, by law they are supposed to offer adaptive instruction and adaptive equipment either through their ski school, or by

contract with a nonprofit ski school like Disabled Sports USA Far West,” says Bowness. “If the ski area is on U.S. Forest Service land, it is under the Rehabilitation Act of 1973, Section 504, and if it is on private property, it is covered under the ADA. This also applies to access. If a three-story lodge has public facilities on the upper floors, they have to provide an elevator and/or ramp.”

Although skiing isn't cheap, with some creativity adaptive skiing can be done on a budget. Two years ago Luke Ekenberg, 20, started traveling from his home in Michigan to California to take lessons at Disabled Sports USA Far West during school breaks. “I was hooked from day one,” says Ekenberg, who is in his fourth year as a T11-12 para. He's so hooked that he recently moved to Truckee and is buying his own ski. He has applied for several grants to help offset the cost [see resources], has applied to be a volunteer at Disabled Sports USA Far West — a benefit of volunteering is earning lift tickets — and he has a goal of learning to become an instructor.

Jennifer Weast had a ski accident at age 16 in 1977 that resulted in C5-6 quadriplegia and her love of being on a mountain skiing taken away. Although adaptive skiing evolved to enable a quad injured at her level to bi-ski by the 1990s, she didn't try it. “A fear of the mountain and the demands of a high school teaching career kept me away for three decades,” she says. In 2010, her brother and a Disabled Sports USA Far West staff member encouraged her to give it a try. “The first day was surreal. With an instructor tethering me, I was able to once again make my own turns and feel the adrenaline I had felt in times past,” she says. “I now ski from the summit. My fear has been replaced with the trust I have in my instructor who holds my life in his hands with tethers. The ability to ski anywhere on the mountain has given me back a missing piece of my spirit that I had long ago buried.” Weast is fortunate that most of her skiing is covered by various forms of scholarships and she is able to ski a dozen times each year. “I live for the winter weekends and now can't imagine my life without my mountain.”

Lesson prices at dedicated adaptive ski schools average \$100 for a two and a half hour private lesson or \$200 for all day, and include lift privilege and equipment. Most dedicated adaptive schools have some type of sliding scale or scholarship program for those who are on a tight budget.

Cross Country Skiing (XC)

To experience the beauty and quiet of nature, get to areas that are inaccessible by chair and get some healthy exercise, adaptive cross country-skiing (XC) is the ticket. An adaptive XC ski consists of a lightweight molded bucket-style seat mounted on two cross-country skis, is the exact width of a standard groomed XC ski trail, and is propelled by pushing with ski poles. Although it sounds difficult, XC skis are easy to propel on a groomed track, actually gliding much easier than a wheelchair. The poling action of XC skiing works neglected muscles in the back of the shoulders, which helps keep shoulders balanced and healthy.

“In the winter I cross-country ski every day. It feels great to be outside and I always feel better when I do it,” says Candace Cable, 61, from Truckee, Calif. Cable, who is in her 40th year as a T10 para, competed in XC skiing in four Paralympics and in 2004 became first American female to win an overall cross-country World Cup Title. Now retired from competition, each winter she travels to different areas to teach and coach cross-country skiing.

“I was a hiker before my injury and thought it was gone forever, but cross-country skiing gives me the same experience of getting out on a trail under my own power to explore wilderness areas,” says Cable. “When I cross-country ski, I realize I'm hiking again. It enables me to go places that no other adaptive device can, or sit in the quietness of the trees, or look at the vastness of the mountains from a valley that I skied into and will climb out of under my own power. It gives me a huge sense of accomplishment.”

“Cross-country is also great exercise since it uses all of the muscles you have control over and brings out some you may not be aware of,” says Cable. “It is also great for balance and core muscles — this is just as true for lower-level quadriplegics.”

One of the people that Cable introduced to cross-country skiing is Pat Cottini, 43, from Chico, Calif. Five years ago Cottini, who is in his 28th year as a C7 quad, was going through a depression after a serious surgery, so Cable invited him up to Tahoe Donner Cross-Country Ski Center near Truckee, Calif. “Being outside in the wilderness and getting exercise picked up my mood and it was fun,” says Cottini. “That was it, I was hooked! I love cruising on the trails. I also found it worked every little muscle I had, which is great.” Soon Cottini purchased his own ski and now he skis a lot. He also started paying it forward and teaches cross-country at Mount Shasta, Calif.

Cable says that many adaptive downhill programs offer cross-country skiing. Also more and more Nordic centers teach adaptive cross country and rent adaptive skis, as they should, because if they offer lessons, they are supposed to offer adaptive lessons and adaptive gear under equal access guidelines.

Snowmobile Touring

If you have a hankering to get into the backcountry with a little less effort, perhaps snowmobile touring is for you. “It is awesome. I've gone a dozen times,” says Matt Feeney, 52, the advancement director of Adaptive Adventures. Feeney explains that a snowmobile is perfect for a para because it is all hand controls, handlebar steering, thumb lever throttle and hand brakes like on a motorcycle, and there are stirrup-type foot rests with non-skid padding to place your feet. Feeney, who's in his 27th year as a T9 para, puts a webbing strap over his legs to secure his feet in place. He snowmobiles at Grand Lake, Colo., an area that has many rental and guide companies. “You can go on a guided tour, or get a map and go straight rental. I can't imagine a rental or guide company having a problem renting to a wheelchair user with decent arm and hand movement,” he says. “I rent and go with a couple buddies and we follow the trail maps.”

One of Feeney's first times out he was having so much fun he went up a hill in deep powder without telling his friends

and got bogged down in about three or four feet of powder snow. “I was about 100 yards from the trail and was stuck for 20 minutes — I got really lucky that a guy came by, heard me yelling and rescued me,” he recalls. “The moral of the story is to never go alone.”

Rick Dean, owner of T Lazy Snowmobile tours in Aspen, Colo., has been providing adaptive snowmobile tours for 26 years. “For a person with arm and hand movement, all that is required is straps to keep their feet in place,” says Dean. “Even if they have limited hand movement they can usually operate the controls.” Dean has one of his guides ride on the back of the snowmobile with people who have higher level injuries or problems balancing. The guide will put his arms around and drive the snow mobile of people with no hand movement. Rates are approximately \$250 for a three-hour tour.

Ken Barrett, president and chief guide of Selkirk Powder at Schweitzer Mountain near Sandpoint, Idaho, has also worked with wheelchair users. “As a guide it is my job to adapt the experience for every person who goes with us. Adaptation and bringing the mountain experience to people is what makes my job worthwhile,” says Barrett. “When somebody has an experience that is new and unique, that is what it is all about.” Rates are approximately \$150 for a three-hour tour.

Arguably the ultimate in snowmobile touring is offered by Arctic Adventure, located an hour north of Montreal, Canada. The company has snowmobiles with custom seats to hold your hips, back and legs in place and offers a seven-day tour of the wilderness areas of Quebec. Your chair is transported on a guide’s snowmobile and each night you lodge in a fully accessible log chalet, complete with an outdoor hot tub overlooking forests and frozen lakes, and fully-catered meals. Additional activities include dog sledding, ice fishing, tubing, and a stop at a ski resort for adaptive skiing. The owner-operator, Nicolas Bourselier, has been guiding individual wheelers and adaptive groups since 2010. The price is \$1,692 — I’m already saving and hoping there is some type of journalist discount.

For snow sports lovers, Mother Nature’s adaptive winter blanket never lasts long enough. Choose a sport, or two or three — and give them a try!

Resources:

- Adaptive Adventures, 877/679-2770; adaptiveadventures.org

Alpine Skiing:

- Disabled Sports USA Far West, 530/581-4161; www.dsusafw.org

Adaptive Ski Manufacturers:

- DynAccess, 484/767-0477; dynaccessltd.com
- Hands On Concepts, 877/375-6257; www.teamhoc.com/sports-equipment
- Enabling Technologies, 303/578-9345; enablingtech.com/pages/products
- Freedom Factory, 262/898-4675; www.freedomfactory.org/index.html

Cross Country Skiing:

- Adaptive Cross Country Skiing Program Map, batchgeo.com/map/1ccf5b1464291f0f31f0e508c3d77883
- Candace Cable Reeve Health Minute Cross Country Ski Videos, www.christopherreeve.org/site/c.ddJFKRNoFiG/b.5848659/k.5E06/Reeve_Foundation_Videos.htm. Click on Reeve Health Minute and scroll down to Cross country sit skiing.
- Enabling Technologies Nordic Skis, 303/578-9345; enablingtech.com/pages/cross-country-ski
- Mount Shasta Nordic Ski Organization, mtshastanordic.org
- Spokes in Motion Nordic Skis and Alpine Skis, 303/922-0605; www.spokesinmotion.com/category/23
- Tahoe Donner Cross Country, 530/587-9400; www.tahoedonner.com/cross-country

Grant Organizations:

- Challenged Athletes Foundation, 858/866-0959; www.challengedathletes.org
- High Fives Foundation, 530/562-4270; highfivesfoundation.org

Snowmobile Tours:

- Arctic Adventure, 450/228-3181; www.arcticadventure.com/en/snowmobile-holidays-canada-and-quebec/wheelchair-snowmobile-holidays-canada/
- Selkirk Powder, 208/263-6959; selkirkpowder.com/snowmobiling-at-schweitzer/
- T Lazy 7, 970/925-4614; www.tlazy7.com/dir/snow.html

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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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