news
sbaMass

Winter 2008
The Newsletter of the Spina Bifida Association of Massachusetts

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Letter from the President

by Brendan Sullivan

Happy New Year! On behalf of the Spina Bifida Association of Massachusetts (sbaMass) I would like to offer each one of our member families warm wishes for the New Year. We hope that all of your wishes and desires come true in 2008.

When last I wrote, we were preparing for the annual sbaMass Holiday Party. I'm happy to report that on a cold winter's afternoon we had more than 75 members of our community on hand to celebrate the holidays. Guests were treated to holiday games, prizes, and a chance to interact with other members of our community. And most importantly, all the children in attendance received a gift from our very special guest, Santa Claus! He has assured us that he will return next December because our party is one of his favorites every year!

I would like to take this occasion to thank two very special members of our community for their incredible dedication to sbaMass. This past December, Mark and Katie Brown graciously hosted a party in their home for friends and family to raise funds for sbaMass. In that one evening more than $11,000 was raised for the Spina Bifida community in Massachusetts. On behalf of sbaMass, I would like to extend a very grateful thank you to the Brown family and their loyal friends for this generous gift. This significant donation will be used to enhance sbaMass' services and programs. Please look for more information on the Brown Family donation later in this newsletter.

Next, I would like to thank John Page for his dedication and commitment to sbaMass on behalf of his daughter, Erin, who has Spina Bifida. John and a number of his loyal friends are undertaking the task of climbing 67 mountain peaks in New England in support of sbaMass. In his arduous task, John is combining his love of his daughter with his love for climbing to raise awareness and support for the Spina Bifida community in New England. For more information about John's climb, please see his update in the newsletter.

Finally, the Board begins its next term this month, and in our next newsletter I look forward to introducing to you the newest Board members.

continued on page 2

Letter from the President

continued from page 1

I hope you enjoy this quarter's newsletter. Remember it contains important information about sbaMass summer events such as the National Conference and our annual Golf Tournament. Please save the dates so we can see you at each.

Wishing you good health and a warm winter season!

Thank You for the Holiday Party Donations!

- Vermont Teddy Bear
- Necco Candy
- Karen Fillingim

Bits & Pieces

by Hyacinth Bellerose

As we are entering the first snow laden winter in many years, this edition of Bits & Pieces focuses on the various winter safety tips rather various issues:

- Diminished sensory abilities and limited ability to maintain body heat require people to be particularly vigilant about staying warm when out in low temperatures.
- Wear multiple layers of clothing, including a scarf around your neck, a winter hat (keep ears covered!), lined boots and two pairs of socks.
- If possible, wear thermal gloves underneath mittens to keep your hands warm.
- Carry a cell phone and keep it relatively warm so that the battery does not drain of power in the cold.
- If you travel in a wheelchair, wrap a small blanket around your legs, tucking it underneath yourself or around your sides. This will help to maintain body heat.
- Wheelchair users may consider purchasing pneumatic tires for better traction. Another alternative is to use standard dirt bicycle tires.
- Use table salt or clay cat litter to clear ramps; rock salt can poison assistance animals and may be slippery (keep emergency stash in your backpack).
- Remove the tires from your wheelchair and shake debris and ice off them before placing them in your vehicle.
- Wipe down any metal surfaces (wheelchair tire rims, walkers, etc.) as soon as possible after returning home. This will prevent rusting.
- If you use any battery or electricity operated equipment, be sure to have backups in place in the case of extended power outages.
- If using canes, walkers, forearm cuffs, or a wheelchair, remember the freezing rain will stick to these aides and make the metal parts especially slippery and very cold to the touch. You may wish to use gripper-driving gloves.
- At crosswalks, be very alert to oncoming traffic as drivers may not be able to stop in time due to the ice and low visibility with sleet and freezing rain.
- If you are not accustomed to heavy wheeling, be very careful in the snow as added exertion could cause you to have a heart attack or stroke.
- Arrange your schedule to limit your exposure to snow and wind chills.
- Check feet, pelvic areas and hands for circulation problems.
- If you use a working assistance dog, have a blanket for him to sit or lay on in the vehicle. Consider a dog coat underneath his regular harness and dog boots.
- Warning signs of hypothermia in adults are shivering, confusion, memory loss, drowsiness, exhaustion, fumbling hands, and slurred speech. In infants, warning signs include bright red, cold skin and very low energy.
- Put a safety flag on your wheelchair to be see over snow banks and during snow.
- Walkers, canes and wheelchairs parts need to be kept clean (baby wipes!) of chemical residue to avoid deterioration of the equipment.
- Wheeled tips on walkers are a winter danger. Try sliding a tennis ball (with a ½ slit) over the front wheels to still allow the walker to move but to slip less.
- For a general listing of winter tips from power outage preparation to a winter precautions kit, check out **www.vrfa.org/_media/pdf/Winter_Safety_Tips.pdf**
- The Ohio Legal Rights Services has an excellent medical preparedness checklist: **www.weathersafety.ohio.gov/EmergencyPreparednessSpecialNeeds2007.aspx**

Youth and Adults Group Update

Resources to Assist in Achieving Independence and Safety

by Jen Kuhar

On Saturday, October 27, 7007, the Spina Bifida Association of Massachusetts Youth and Adults Group held its Third Annual Lunch and Learn, entitled “Taking Charge & Achieving Independence”, at the Wellesley Community Center in Wellesley. We were fortunate to have three outstanding speakers join us. The day began with **Lucy Bayard**, Senior Training Specialist with the Institute for Community Inclusion National Service Inclusion Project. Officer **Brian Spencer**, Youth/Safety Officer for the Wellesley Police Department, followed with a discussion on Emergency Preparedness. After lunch, **Barbara Lee**, a Benefit Specialist with Resource Partnership explained that folks do not lose benefits by working and broke down the policies for SSI and SSDI benefits and various work incentives.

National Service Inclusion Project:
Lucy Bayard spoke of the many benefits of volunteering. Volunteering helps folks develop skills that could potentially lead to employment. Volunteering can be a way to make new friends, thus improving communication and interpersonal skills, which just might help you obtain that dream job. We all agreed that volunteering can be a big self-esteem booster. Folks tend to feel good when they are helping others. Lucy talked about the AmeriCorps and AmeriCorps VISTA programs. Some opportunities even offer stipends and housing. Some lead to permanent employment. The sky is the limit and by contacting **Christine Robles** at the AmeriCorps State Commission here in Massachusetts at (617) 565-7017, you can work with them to find the perfect opportunity for you. Visit **www.communityinclusion.org** for more information about the National Service Inclusion Project.

Emergency Preparedness:
Officer Brian Spencer gave us many useful tips in planning for Emergency situations. Of course this is not something we hope to ever have to deal with, but it is important to have a plan in place. He gave us many tips, but here are some of the highlights:

- Have an evacuation plan in place. Let your local Fire Department and Police Department know your situation. Work with your employer or school to develop a plan should the building need to be evacuated.
- Have all of your important documents and items (such as medications, medical supplies) together in a bag or backpack so that you can quickly grab it and evacuate. Important papers, such as medical records, should be stored in a fireproof safe that is easily transported.
- Have a three-day food and water supply for each person in your home. Keep a First Aid Kit, batteries and flashlights on hand.
- Have a contact labeled “ICE” programmed in your phone. Emergency personnel can check your phone for this listing and call your emergency contact.
- Remember, landlines are directly connected to the 911 system and emergency personnel will be able to determine your exact location if you call 911 from a landline.

Social Security Work Incentives:
Barbara Lee did an amazing job in breaking down the Social Security Programs, focusing on the many Work Incentives offered by the Program. There are even special incentives for students. Barbara emphasized folks who work and receive SSI or SSDI payments will have more money in their pocket than if they do not work. The Program offers incentives such as Trial Work Periods, reimbursement for Impairment Related Work Expenses (IRWEs), and Plan to Achieve Self-Support (PASS). Did you know that by working to develop an SSA approved PASS Plan, you can set aside funds to accomplish a goal such as purchasing a car or starting a business and not have the level of your benefits reduced? For most of us, the Social Security Programs can be

continued on next page

overwhelming to navigate on our own. However, there are many resources available to help you get started! Resource partnership is a non-profit Organization in Massachusetts that offers job placement services as well as assistance in applying for Social Security benefits. Give them a call today at 1-877-YES WORK or visit their website at **www.resourcepartnership.org**. You can also visit **www.socialsecurity.gov**. You don't want to miss out on the many opportunities available to you!

Upcoming 2008 YAG Events

- sbaMass YAG goes south! Join us on Saturday, March 1, 2008 at 1PM for lunch at Uno Chicago Grill at the South Shore Plaza in Braintree, MA. Friends, siblings and spouses are welcome! Kindly RSVP by Wednesday, February 27, 2008 to edugan@sbaMass.org or (888) 479-1900.
- Planning for 2008 is underway, but in order to continue to bring the same level of programming as in past years, we will need your help. Contact Jen Kuhar at jkuhar@sbaMass.org or at 888-479-1900 to find out more about how you can help! There are many volunteer opportunities available. Stay tuned for more information about upcoming events. Be sure to visit our website **www.sbamass.org** often so you don't miss out!

Thanks! Thanks!

Thank you!

Roche Brothers, Wellesley, MA

Outdoor Explorations

Baker's Choice, Wellesley, MA

for your kind donations to the
YAG Let's Talk and Lunch and
Learn Days!

sbaMass ANNUAL BENEFITS PROGRAM
$500 for 2008

For the **OFFICIAL POSTING and/or APPLICATION (both posted on www.sbaMass.org) and/or Questions**, provide your name, address, phone number, email address (if available) AND your request (Annual Benefits Package) to edugan@sbaMass.org or fax (978) 926-7700 or leave the information and request in a phone message at (888) 479-1900.

She bridges the gap for parents, doctors

by Andrew Rimas, Globe Correspondent

Dr. Paige Church believes that her parents' "Yankee wisdom" is what gave her a normal life. Born with spina bifida, a dangerous birth malformation that required repeated surgeries throughout her childhood, her parents would have been excused for treating her like an invalid.

But they didn't.

"I had to make my own bed the day after I had surgery," said Church, 35. "When I was 14, my Mom said, 'You can let this shape you and make you less of a person, or you can do something good for the world.'"

Church now runs the Neonatal Intensive Care Unit follow-up program at Floating Hospital for Children. After a premature baby is released from the hospital, part of Tufts-New England Medical Center, Church is the one who bridges the gap between the families and their primary care physicians -- checking on the baby's feeding, breathing, and development, making sure that parents have the resources their child needs.

"Boston is the epicenter of medicine, with some of the brightest minds in the world in this city," she said. "But that doesn't mean healthcare is accessible. Especially for parents of kids with complex medical problems."

A native of Vermont, Church grew up in the country town of Shelburne. Her illness meant that she spent a lot of time being assessed by specialists. "But no one looked at me as a whole kid," she said. "Most doctors don't have the time allotments to do that effectively. As a physician, I wanted to look at the whole kid, development and everything."

She cited an example of a patient who wasn't growing properly. Doctors studied the boy's gastrointestinal tract to no avail. Only by having the patience to spend time with the boy and getting a thorough understanding of his case did Church and her colleagues realize that the boy was autistic, and wasn't growing because he had selected only a few foods to eat.

To help her treat the whole patient, Church trained in a rare double-specialty: developmental pediatrics and neonatology (newborn care).

"She's a clever duck," said Simon Michael, Church's mentor and director of the hospital's training program in Neonatal-Perinatal Medicine. "She has an unusual background in being trained in two seemingly unconnected areas, but a lot of these kids have developmental issues that arise as a result of prematurity."

Kevin Petit, interim pediatrician in chief for Floating Hospital, said Church hatched up the idea to combine the two specialties. "She's proving the interface of developmental pediatrics and neonatology," he said. "A lot of these kids have subtle problems that aren't easily picked up, and then they evolve into more significant problems as they get older. Having someone with Paige's unique training means these kids don't fall through the cracks."

Lynne Bopp is the mother of one of Church's patients.

"My son Aidan was born at 24 weeks at 1 pound, 9 ounces. He was in the NICU for 103 days," Bopp said. She credited Church with the fact that her son is now thriving. "She would sit and talk with us after her shift was over. She gave us a lot of hope," Bopp said. "You almost forgot that she was a doctor."

Last month, Church won the hospital's Sidney S. Gellis, MD, Young Physician's Award in recognition of her clinical work. "Having been a patient, I know how painful, frustrating, and scary it can be," she said. "That's stuff I understand very well."

Hometown: Melrose

Family: Husband, Erik. Daughter, Elizabeth, 8 months. Yellow Labrador, Ty, 4.

Hobbies: Fly-fishing. "Because of my medical history, I didn't have the strength to do some [more strenuous] stuff."

On silver linings: "The nice thing about my birth defect is that I get a re-education every four or five years [in what it means to be a patient.] So if I ever lose my sensitivities, I get reintroduced."

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2008 SPINA BIFIDA ASSOCIATION of Massachusetts

CHARITABLE EVENT

FOURTH ANNUAL GOLF TOURNAMENT

SKY MEADOW COUNTRY CLUB

Nashua, New Hampshire
www.skymeadow.com

Monday, May 5, 2008 Shotgun Start 1:30 pm

GOLFERS: $25 IN RAFFLE TICKETS FOR PAID SIGNUP BY MARCH 1st, 2008!

SPONSORS NEEDED: Major Sponsors to Friends of the Spina Bifida Association of Massachusetts

AUCTION ITEMS NEEDED: Sports tickets, vacation home stay, etc.

CELEBRITIES: Include a famous sports, business or entertainment figure in your foursome and you both play for free!

VOLUNTEERS: Positions are open for assistance prior to and during the day of the event.

CONTACT US TODAY!

CONTACT INFORMATION

Spina Bifida Asssociation of Massachusetts

Ellen Dugan, Operations Associate
Website: **www.sbaMass.org** (all forms and details)

Toll Free: (888) 479-1900
Fax: (978) 926-7700

Tournament Co-Chairs

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Cleveland, Waters and Bass PA
hillisj@cwpa.com
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CONTACT US TODAY!

Healthcare costs of Spina Bifida: An overview

by Ginny Briggs

My daughter’s orthopedist recently advised us to get a second pair of braces for her to sleep in at night. The new pair would help her legs and feet grow more normally without limiting her walking ability during the day. Of course, we will do anything we can to help her, but braces are expensive and insurance doesn’t always cover the cost. Our insurance allows us $750 per year for braces, so if we can make it a full year, we must contribute an additional $250 out of our own pocket to make up the difference. Now, with another pair needed at the same time, we will be completely financially responsible for the second. This is an example of one of the many expenses not covered by insurance that someone with Spina Bifida will be responsible for on a regular basis throughout their life. A recent study evaluated the healthcare costs of people with Spina Bifida. We know the costs are usually high, but what most of us probably don’t know is how much we will have to pay for ourselves and how the costs change as we get older. We may be able to plan our healthcare futures more effectively if we know what to expect financially.

This study was published by the National Center of Birth Defects at the Center For Disease Control in 2007 and was presented at the Spina Bifida Conference in Atlanta in 2006. The highest overall expenses were for children under age 1 where the average yearly cost for inpatient services (overnight hospital stays, surgeries, tests, etc.) was over $40,000. Families paid about $3,000 of that cost out of their own pockets. As patients got older, the total inpatient costs were a lot lower and the amount that families had to pay was substantially reduced. Outpatient visits (day surgeries, doctor’s appointments, tests, etc.) were a different story where families of kids age 1-17 had the highest out of pocket expenses (total yearly cost $7,939, patient out of pocket $886). Table 1 highlights the expenses of both inpatient and outpatient costs:

Table 1: Average healthcare costs for people with spina bifida

	Age <1	Age 1-17	Age 18-44	Age 45-64
Inpatient				
Insurance	$37,045	$5,943	$6,375	$3,667
Other	$0	$49	$456	$1,582
Patient out-of-pocket	$3,168	$470	$758	$326
Total	$40,213	$6,462	$7,589	$5,575
Outpatient				
Insurance	$8,038	$6,931	$5,657	$5,883
Other	$0	$122	$284	$573
Patient out-of-pocket	$691	$886	$817	$806
Total	$8,729	$7,939	$6,758	$7,262

Prescription drug costs also increase with age, from a total of $660 per year for children under age 1 to $2,841 per year for people age 45 to 64. The responsibility of the patient to pay for some of those medications also increases with age. Table 2 shows how medications are paid for:

Table 2: Average prescription drug costs for people with spina bifida

	Age <1	Age 1-17	Age 18-44	Age 45-64
Insurance	$560	$678	$1,264	$2,372
Patient out-of-pocket	$100	$163	$258	$469
Total	$660	$841	$1,522	$2,841

Though the amount of out of pocket expenses may seem low compared to the total cost per year, it is still substantial and can have devastating effects on people with limited incomes. We may learn two important lessons from this report. First, if employers offer a choice of healthplans, this study can provide families and individuals with spina bifida a guide to choose the right plan for them. For example, we chose a healthplan that only gave us $750 per year for braces, but it had lower monthly costs. Now that we know we may need two pairs of braces every year, we will switch our healthplan during the next enrollment period to one that has a higher benefit. Second, there are other sources of support for healthcare costs that are worth applying for. For example, sbaMass offers up to $500 per year for medical (and other) expenses not covered by insurance. Another source is United Healthcare Children's Foundation which has a benefit available for children who need medical services not covered (or not completely covered) by insurance (the website is at **www.uhccf.org/apply.html**). sbaMass will continue to publish information about other sources in this newsletter as they become available. We encourage our members to let us know about other programs they may hear about.

REFERENCE: Health care expenditures of children and adults with spina bifida in a privately insured U.S. population. Birth Defects Res A Clin Mol Teratol. 2007 Jul;79(7):552-8.

Thanks to the following companies for their Matching Gifts

Bank of America
Global America
Thomson Financial

Are you Seeking Funding for Post-Secondary Opportunities?

Three impressive resources for additional information on scholarships, financial aid and resources are listed below. All provide a variety of information on applying for financial assistance and possible funding sources. Additional information can be obtained by contacting edugan@sbaMass.org. Also watch the sbaMass website **www.sbaMass.org**, announcements from SBA and sbaMass regarding scholarship opportunities offered.

College Funding Strategies for Students with Disabilities
www.washington.edu/doit/Brochures/PDF/financial-aid.pdf
A six-page document by the University of Washington providing a good list of scholarships and resources for students with disabilities

Creating Options: A Resource on Financial Aid for Students with Disabilities (2007)
www.heath.gwu.edu/node/188
www.heath.gwu.edu/files/active/0/2007_creating_options.pdf
The latest edition of this popular resource paper features up-to-date information about federal financial aid programs, describes the relationship between state vocational rehabilitation agencies and the financial aid process, and lists organizations that offer disability-related grants and scholarships for postsecondary education. The paper suggests other sources of financial assistance for individuals with disabilities and recommends web sites where students will find additional financial aid information. Also included is a precollege financial aid checklist to help students plan and manage a funding search.

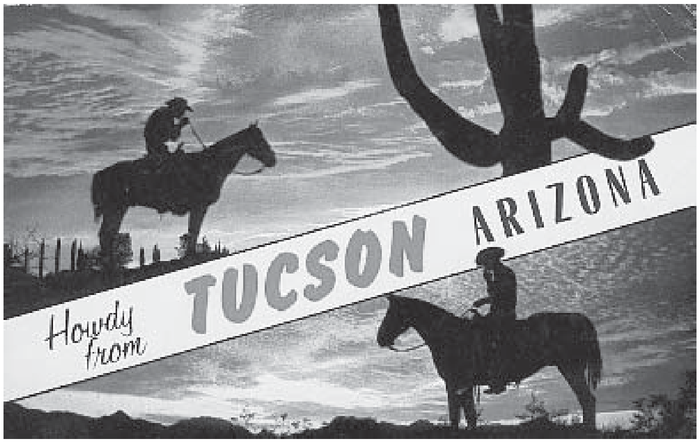
HEATH Resource Center
www.heath.gwu.edu/
George Washington University has received a grant from the U.S. Department of Education's Office of Special Education and Rehabilitative Services to operate the National Clearinghouse on Postsecondary Education for Individuals with Disabilities, known as the HEATH Resource Center. The web page contains information about funding opportunities along with many other resources.

SBA 35th National Conference
Tucson, Arizona
June 22-25, 2008

at the

JW Marriott Starpass Resort

(www.jwmarriottstarrpass.com)



START PLANNING NOW!

Check out the conference scholarship announcement!!!!!

The Conference: Instead of rehashing my ongoing praise for Conference, I'll just say that if you or a loved one has Spina Bifida, it would be shocking if you were to return from conference disappointed in the programming.

The Resort: The 2008 Conference is a true resort (not just a conference hotel) in Tucson, Arizona. It will take longer to get there but the resort looks worth the trip! Every luxurious room has a private patio or balcony coupled with magnificent Tucson views.

Onsite Activities (READ AND DREAM!):

- Two sparkling pools overlooking the surrounding mountain ranges and city below, Two whirlpools, Children's splash area with pop-up jets, Stunning views of the Sonoran Desert, Brand new Lazy River and Water Park
- Luxury Spa and Fitness Center
- Culinary Concepts Cooking Class, Terry DeWald Cactus Garden Design, Art of Entertaining, Jewelry Making Class, Maderas Gallery Shopping Excursion
- Golf, Tennis, Hiking and Biking, Basketball, Geocaching, Table Tennis Croquet, Badminton, Volleyball, Arcade, Horseback Riding

With all of this, just imagine how wonderful Kids Camp will be!

More information: Updated local information, ground transportation, flight cost and website links are under Conference at **www.sbaMass.org**.

A personal subjective note: This hotel seems much more user friendly than the past two conferences as the conference halls are in the same hotel as the guest rooms and the layout does not appear to be confusing. I would consider the atmosphere as perfect as it provides a real feeling of vacation. Please note however, the implications of the hotel not being downtown. In order to eat in a place other than the three onsite restaurants, it will be necessary to get transportation for the 6 mile ride into to the downtown area. Watch the conference information page on the website as I will be updating it with more information as to local transportation and dining options. I'm not trying to discourage people but just to assist in planning as it will be a different experience from the city conferences where McDonald's and Walgreens are not too far away!

Hyacinth Bellerose

sbaMass REALLY Wants You to go to the SBA National Conference this June in Tucson, Arizona!

sbaMass will even help pay for it!

The SBA Conference is the biggest event of the year and you can be a part of it!

Funds are now available: 7 Scholarships of $1500 each*

You need only provide application with:

- Letter with reasons for wanting to attend the conference
- Details of persons to attend and anticipated costs
- Whether, or the number of years since, you previously attended conference (this will be a factor in determining the scholarship)
- Yout willingness to write an article, take pictures or someshow share your experience
- Signed application / contract (see below)

For the **OFFICIAL POSTING and/or APPLICATION (both posted on www.sbaMass.org) and/or Questions**, provide your name, address, phone number, e-mail address (if available) AND your request (SBA Conference Scholarship Package) to edugan@sbaMass.org or fax (978) 926-7700 or leave the information and request in a phone message at (888) 479-1900.
Submit application to the above e-mail/fax or mail it to:

sbaMass
733 Turnpike Street, #282
North Andover, MA 01845

Important Dates

SBA 2008 Annual Conference
June 22 - 25, 2008
Tucson, AZ

Application Submission
Deadline: April 4, 2008

Notification Deadline to
Scholarship Awardees:
May 1, 2008

Formal Announcement at
sbaMass Golf Tournament:
May 5, 2008

Thank You!!!!!!!

Once again the Board of Directors would like to thank **Mark and Katie Brown** for their tremendous fundraising effort on behalf of sbaMass. The Browns hosted their Second Annual Holiday Party, raising over $11,000 for sbaMass. These funds will allow sbaMass to continue to provide much needed support to individuals with Spina Bifida and their families. Thank you to the Brown Family!

climbing4SpinaBifida Update

by John Paige

Holiday Greetings friends and supporters! We have a lot of news to share with you this month. Starting off is our Coast to Coast Expeditions! We have a 4-member team that will climb the highest 10 Peaks in the Cascade Range. The team members are Expedition Leader **Don Enos** from Ferndale Washington. Don is an avid climber and is also one of our sponsors who wanted more than to just sponsor. Don works for Seattle Manufacturing Corporation (SMC). Please visit their website at **www.smcgear.net**.

Age: 35
Hometown: Ferndale, WA
Occupation: International Sales & Marketing Manager
Hobbies: Photographer, mountaineering, fishing, hiking, cycling, rock climbing, dual sport adventure riding
Volunteer Activities: Cascade Christian Services, Youth Soccer Coach, Youth Mentor

Second we have **Jason Kammerer** who also works for S.M.C.

Age: 27
Hometown: Bellingham, WA
Occupation: Project Engineer for SMC
Hobbies: Ski mountaineering, fly fishing, hiking, cycling, camping, rock climbing, vacationing
Volunteer Activities: Bellingham Mountain Rescue, Ski Patrol, Youth Mentor

Next we have **Gwen Hobbs** and **Brian Janes**:

Gwen Hobbs is an occupational therapist by trade and an adventurer by life. After graduating from the University of Indianapolis in 2006 with a Master’s in Occupational Therapy she moved to northern California to pursue a rewarding career in Siskiyou County, which consequently is in great need of occupational therapists. She is currently working a generalist position that includes in-patient, out-patient, and home health care. Although the population in primarily elderly, Gwen in familiar with the disease process and the role that occupational therapy may play throughout the life span of a person affected by Spina Bifida. Gwen has been a rock climber for several years with ties to the Red River Gorge in KY and has taken on mountaineering as a new endeavor since 2005, including the pleasure of summiting Mt. Shasta for the first time in May 2007. A per chance meeting over the internet with John Page has led us to the adventure of a lifetime: Bringing Spina Bifida to the spotlight while concurrently supporting the passionate profession of occupational therapy and adding a little adventure to keep it interesting.

Brian Janes is a wildland firefighter for the US Forest Service and a 2002 graduate of Humboldt State University. Spending most of his time in the wilderness climbing and backpacking prompted Brian to study emergency medicine. He has been trained as an EMT for 6 years and a Wilderness EMT for 4 years. Rock climbing/caving since 2000 and mountaineering since 2002, living in Northern California has allowed access to climbing areas all over the western coast. Mountaineering summits include: Mt. Shasta-14,162 ft (8 accents), Mt. Hood-11,249, Mt. Jefferson-10,497ft, Three Finger Jack-7,841ft, Mt. Thielsen 9,184 ft, Mt. McLoughlin-9,495 ft. Climbing trips include: Mt. Rainer-14,410 ft (2 days crevasse rescue training), Mt. Whitney-14,494 ft (3 trips). Brian is excited to be able to use mountaineering to help promote awareness for Spina Bifida and to help others accomplish their dreams, no matter how high.

We have been busy gearing up and seeking sponsors for our West Coast Team and planning our climbs. Our website is doing very well and our MySpace has almost 16,000 views worldwide. So we are gaining in our quest for worldwide awareness. The list of sponsors has grown to nearly 50 sponsors. We have a great group of sponsors and we would appreciate it if you could stop by their website and show them the support they have given us.

I would like to single out a few sponsors who have gone above and beyond for our teams.

Neil Johal at Mount 7: **www.mountseven.com**
Rick Galas at Manzella: **www.manzella.com**
Lisa Eaton at Jetboil: **www.jetboil.com**
Al Whitworth at White Sierra: **www.whitesierra.com**
Nick Yardley at Julbo: **www.julbousa.com**
Tim Pratt at Alpine Aire: **www.aa-foods.com**
Tom Reynolds at Nemo: **www.nemoequipment.com**
Martin Schamboeck at Suunto: **www.suunto.com/outdoor**

Martin will be joining us for a peak or 2 this coming summer. Martin has become a great friend as well as a great sponsor!

We also had a partner change on the East Coast Team and joining me will be my brother **Norman Page**. Norm is a U.S. Army Veteran and an avid outdoorsman. As our teams are set to go, the West Coast Team will begin climbing in the next month or two as will we. We are itching to get started and spreading the message and as we stated anybody can climb with the teams on any given day and those of you who can't join us will be with us in our hearts.

On other notes we are having two flags with our sponsors logo on them to carry to the top of each summit. At the conclusion of our coast to coast we will auction the flags on an upcoming Ebay site that our very own sbaMass will be running. I will be carrying a picture of my daughter **Erin** to the top of each summit and leaving it there in honor of her and her will to survive. The team out West will also place the same picture on each of their Summits of Erin and any momentums they would like to leave.

That is the news as of today and we will have more news posted on our website as often as we can. We look forward to meeting some of you out there and we hope you will help us raise awareness and funds for sbaMass. We wish you all a happy, healthy 2008!

John Page
Climbing for Spina Bifida
Expedition Leader
802-698-8042
odessa2001@comcast.net
www.climbing4spinabifida.org
P.O. Box 19
Hartford,Vermont 05047

Jean Driscoll Scholarship Offered by the Spina Bifida Association of Massachusetts

The sbaMass Board of Directors is now accepting applications for the Annual Jean Driscoll Scholarship. The sbaMass offers this **$1000 scholarship** as a tribute to Jean Driscoll, an eight-time Boston Marathon Champion and adult with spina bifida. **The scholarship may be used for educational, developmental or assistive programs or needs and will be awarded to a sbaMass student with spina bifida who best demonstrates the character and determination of the scholarship's namesake.**

Jean Driscoll, who was born with Spina Bifida, is an accomplished athlete and speaker who is known around the world. She has enjoyed a life many people can only dream about experiencing. Jean is an Olympic athlete who won Silver medals in the 1992 and 1996 Summer Olympic Games. She is a world record holder in the 10,000 meter track event as well as the 10K and marathon road racing distances. She has won the Boston Marathon eight times and is the only person in Boston's 105 year history to achieve this feat. She even has a street named after her in Champaign, IL and a park pavilion named after her in Urbana, IL.

PROCEDURE

1. **Completed Application (including Personal Statement) and Recommendation Letter must be submitted by *May 15, 2008*.**
2. The Personal Statement must be at least two paragraphs describing your goals in life, future educational pursuits, and anything else you feel would be helpful for the Scholarship Committee to know about you. The scholarship will be awarded to a person who, like Jean Driscoll, is achieving his/her goals despite any limitations imposed by spina bifida.
3. The recipient shall be notified of their award in mid-June and a formal announcement will be made at the sbaMass summer picnic in July.

For the OFFICIAL POSTING and APPLICATION, see **www.sbaMass.org**, OR email edugan@sbaMass.org, call (888) 479-1900 or fax (978) 926-7700 and request the Jean Driscoll Scholarship Package. Be sure to include your name, address, and phone number and (if available) e-mail address.

Contacts

sbaMass Tel. (toll-free) **(888) 479-1900**
sbaMass Fax **(978) 926-7700**

SBA Tel. (toll-free) **(800) 621-3141**

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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 Massachusetts nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The sbaMass 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 sbaMass does not employ medical personnel in its organization.

We're Looking for Office Space!

The SBA of Massachusetts is continuing to seek free or low cost office space. The ideal space would be located on or near Route 128, (accessible to The RIDE), and include space for 3 desks, meeting space to accommodate up to 20, wheelchair accessible, 24/7 access and accessible restrooms. Shared space with another non-profit or business will be considered.

Please contact Ellen Dugan, Operations Associate,
if you or someone you know can help!
(888) 479-1900 or edugan@sbaMass.org

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