

Summer 2008

The Newsletter of the Spina Bifida Association of Massachusetts

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**And More!**

## sbaMass

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## YEARS

## 1971-2008

## The sbaMass Fourth Annual Golf Tournament Recap

by Hyacinth Bellerose

**A**hhh... the golf tournament. Our golfers and volunteers were thrilled with a perfect day for the fourth year in a row!!!! We had many return players but also attracted some new players this year. We truly appreciated everyone's involvement during this year in which many people's finances are very tight. Our hole in one sponsor spot was quickly taken this year by **Aquatic Pools of Tyngsboro** and our sponsors, golfers and bidders were very generous.

The sbaMass is pleased to announce that we made over \$10,000 with 20 less players than last year. The 84 players that turned out were treated to lunch, golf, dinner and entertainment by **Jeremy Bell**, a national comedian (see [www.amaninaskirt.com](http://www.amaninaskirt.com)). Jeremy Bell hosted our auction which was highlighted by Red Sox Tickets, a piece of jewelry from **DePrisco Jewelers**, a full year membership to the **Barbershop Lounge**, and much more. Each year the event keeps improving thanks to increased numbers of volunteers and sponsors and the continuous support of our golfers that tend to return year after year.

For the real story, see the pictures in this newsletter and on the website. They show the feeling of being more than any words. Let's get ready for next year!!!

The sbaMass and the Golf Committee sincerely thank our sponsors, volunteers and golfers. Your contributions allow our families to attend the National Spina Bifida Conference for medical, social and practical seminars and programs as well as the experience of meeting many other people with similar issues from across the country. Thank you.





## Entertainment Sponsor

Evelyn A. Packard & P.K. Packard

## Hole in-One Sponsor

Aquatic Pools



## Auction Sponsors

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## Hole Sponsors

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# Letter from the President

by Brendan Sullivan

**H**ello sbaMass! Welcome to summer! And with summer means the annual SBA Conference. By the time you read this newsletter a strong contingent from Massachusetts (many using the special conference scholarship and annual benefits program from sbaMass) will have traveled to Tucson, Arizona to participate in SBA's 35th National Conference. This year's conference has a theme of "Building a Brighter Future" – a brighter future for SBA, its member chapters, and for each individual and family living with Spina Bifida in our country. In our own chapter, the theme also has a very pertinent meaning.

I know I have spoken to his skills and dedication in this newsletter before, but **Brian Packard**, recent past President of sbaMass, has made his home chapter proud once again. In Tucson, Brian will be recognized as this year's **Outstanding Spina Bifida Champion within SBA**. Brian's commitment and work to improve sbaMass during his term as President is not news to our chapter, but now his tireless work ethic, charity, and professionalism will be known to all in the Spina Bifida community. On behalf of sbaMass, I offer congratulations to Brian on this distinct honor and for being such a great representative of our chapter.

In this newsletter you will read many interesting news stories and articles. You'll see a recap of our annual golf tournament and see how generous donors and volunteers came together for a wonderful day that raised thousands of dollars for sbaMass. You'll also read about another marquee event of every summer, the **Annual sbaMass Summer Picnic!** This year's event is being held on **July 19th at Danehy Park in Cambridge, MA**.

We hope that you are having an enjoyable summer - we'll see you soon and if you have any questions before we see you, please contact us!

## Jen Kuhar - Unsung Heroine

by Ellen Dugan

**T**he Massachusetts Commission on the Status of Women (MCSW) is proud to announce that 287 Community Unsung Heroines of 2008 were chosen from cities and towns across the Commonwealth and were recognized for their outstanding contributions to their organizations and communities in a ceremony on Wednesday, May 14, 2008, at the State House in Boston. The ceremony included a speaking program with a keynote address delivered by Attorney General Martha Coakley. **Jen Kuhar**, Vice President of the sbaMass Board was the **2008 Heroine for Framingham**. These 286 Unsung Heroines were carefully selected from nearly 600 nominations to be honored for selflessly making a difference in the lives of others.

"Our Unsung Heroines are women who don't make the news, but make the difference in their communities, businesses, or volunteer endeavors. They are the women who quietly, without fanfare or recognition and usually behind the scenes, use their time, talent, spirit and enthusiasm to enrich the lives of others," said Linda Brantley, MCSW Executive Director. "We are awed by the fabulous work women across the Commonwealth are doing and thankful to the many nominators who brought these incredible women to our attention."

The Massachusetts Commission on the Status of Women is an independent state agency that was legislatively created in 1998 to advance women of the Commonwealth to full equality in all areas of life and to promote their rights and opportunities. The MCSW provides a permanent, effective voice for the women of Massachusetts.

The Spina Bifida Association of Massachusetts is grateful to Jen for her ongoing commitment to sbaMass. Congratulations JEN!



# Team sbaMass Returns to Falmouth Road Race!



Based on the great success our running team had in last year's Falmouth Road Race, the event's coordinators have invited us back to run the 36th Falmouth Road Race on Sunday, August 10th. Our 22 runners raised over \$30,000 in 2007, and this year we have been granted 25 charity entries! The fundraising and awareness our 2008 team will create should eclipse last year's. If you are on the Cape this summer, please come out to cheer us along the 7-mile course. We will, as always, be wearing shamelessly bright running singlets so you can spot us from a mile away. If you are interested in becoming a member of our official running team, please contact Ellen Dugan at [edugan@sbaMass.org](mailto:edugan@sbaMass.org).

## *Congratulations Brian!*

It is my great pleasure to tell you that SBA has recognized something that we on the Board have known for quite some time, Brian you are an Outstanding Champion for Spina Bifida. You have been named the recipient of the individual recognition of Outstanding Spina Bifida Champion for SBA. The entire Board submitted your nomination and we couldn't be happier for this national recognition of all that you do on behalf of our membership.

To quote the award criteria, the Outstanding Spina Bifida Champion is "a volunteer who exhibits outstanding support and/or leadership". Speaking on behalf of the Board, this description summarizes our impression of your great work during your time on the Board.

Brian, congratulations on this honor. Knowing you, you will deflect credit to others, but we all know better. You deserve this and so much more for what you do on behalf of Katie and others. Speaking personally, I know that I would have never run a marathon if not for meeting you. So for that, I owe you an enormous debt of gratitude.

The award will be given out on the Wednesday of the National Conference in Arizona. I hope you can attend!

Again, congrats Brian! I join with the entire Board in saying well deserved!

Sincerely,

Brendan

### **\*\*SAVE THE DATE\*\* NEW PARENT/CHILD PROGRAMMING!**

**Sept 27 12:30 - 4PM** for Parents and their kids with Spina Bifida ages 7-12.

Location: Children's Hospital Boston - Byers A&B

**Nov 1st 12:30 - 4PM** for Parents and their Kids with Spina Bifida ages 13-17.

Location: Children's Hospital Boston - Byers A&B.

*Both days will tentatively include concurrent programming for parents as well as the children with S.B. Volunteers are needed to assist with both days. If you know someone, or are interested in helping out, please let us know!*

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# Youth and Adults Group Update

## Tips to Getting the Most Out of Your Health Care Visits

Reprinted from *Heath Guide for Adults Living with Spina Bifida*, published by Spina Bifida Association, 2005.

**T**he single most important way you can stay healthy is to be an active member of your own health care team. Here are some tips to help you and your doctor become partners in improving your health care.

### **Preparing for Your Appointment**

- Use your Personal Health Care Record\*, including completing the medication form.
- Ask what information the health care provider will need, such as x-ray films, test results, and medical records.
- If you have a case manager, ask him or her to come to the appointment.

### **Give Information – Don’t Wait to Be Asked!**

- You know important things about how you feel and your health history. Tell your doctor what you think he or she needs to know.
- It is important to tell your doctor personal information – even if it makes you feel embarrassed or uncomfortable. It’s okay to speak openly with your health care providers.
- Bring your Personal Health Care Record with you and keep it up to date. Have a copy placed in your medical record.

### **Get Information – Ask Questions**

- It’s important to ask questions. If you don’t, your doctor may think you understand everything.
- Write down your questions before your visit. List the most important ones first to make sure they get asked and answered.
- You might want to bring someone with you to help you ask questions. This person can also help you understand and/or remember the answers.
- Ask your doctor to draw pictures if that might help explain something.
- Take notes. Use your Personal Health Care Record to keep your notes in one place.
- Some doctors do not mind if you bring a tape recorder to help you remember things. But always ask first.

### **Take Information Home**

- Ask for written instructions.
- Your doctor may also have brochures, audiotapes, or videotapes that can help you. If not, ask how you can get such materials.

### **Once You Leave the Doctor’s Office, Follow Up**

- If you have questions, call.
- If your symptoms get worse or if you have problems with your medicines, call.
- If you had tests and do not hear from your doctor, call for your test results.
- If your doctor wants you to have certain tests, make appointments at the lab or other offices to get them done.
- If your doctor said you should see a specialist, make an appointment.

### **TAKE HOME MESSAGE**

Don’t be afraid to ask questions. It’s important to understand the information you get during a visit. Take notes, get information to take home to read later, and follow up with appointments.

\*A copy of Personal Health Care Record can be found in the *Heath Guide for Adults Living with Spina Bifida*, published by the Spina Bifida Association or by contacting the Spina Bifida Association of Massachusetts. You may prefer to use your own healthcare tracking mechanism to maintain your medical history.

NOTE: This information provided is for informational purposes only. It is not intended to replace, and should not be interpreted or relied upon as medical or professional advice.

## Upcoming sbaMass YAG Events

**Saturday, July 19, 2008** – Annual Picnic, Danehy Park, Cambridge, MA 12:30PM. Don't forget your sunscreen!

**Sunday, August 10, 2008** – A day at the ball park! Lowell Spinners vs. Hudson Valley – LeLacheur Park, Lowell, MA. Gates open at noon and the game starts at 1:35PM. Optional donation of \$5 per ticket. Limited Seating – reserve seats (limit 2 per person) no later than July 28, 2008 by emailing [jkuhar@sbamass.org](mailto:jkuhar@sbamass.org) or calling (888) 479-1900.

**Saturday, September 13, 2008** – Lunch at 99 Restaurant, Saugus, MA 1:00PM. A great opportunity to meet new people, catch up with old friends and enjoy some delicious food!

**Saturday, October 25, 2008** – Annual Lunch and Learn. Morse Institute Library, Natick, MA. Stay tuned for more information!

**Sunday, December 7, 2008** – Holiday Party, Hampton Inn- Natick, MA. You will not want to miss this annual tradition!

## *Thank you!*

Thank you to the the Air National Guard Munitions Community for their recent fund raising effort. At a recent conference 150 individuals from the Munitions community attended a separate event and donated funds in recognition of one of their members from Massachusetts and his daughter who has Spina Bifida. Funds were raised to help further the understanding of Spina Bifida. The personnel organizing this effort were SMSgt David Bowman and MSgt Paul Duit. Thank you to the Munitions community and their support of sbaMass.

## ADOPT-A-GHOST

The sbaMass will be conducting a Spina Bifida fundraising and awareness campaign in October through our **Adopt-a-Ghost** program. **Adopt-a-Ghost** program consists of offering small paper ghosts for sale in your community. It relies on building relationships between sbaMass and stores, restaurants and businesses in our communities. The program is easy to participate in by looking to your local businesses to put ghosts up for adoption. It can also be included at larger events at schools, colleges, boys and girls clubs and other venues. If you are interested in promoting this program in your community, contact Ellen Dugan at [edugan@sbaMass.org](mailto:edugan@sbaMass.org) or (888) 479-1900.

## **Volunteers Needed for Short Term Projects - from home!**

*Are you available to assist sbaMass with some short term projects requiring computer skills?*

We need assistance developing databases, organizing resource information, online research, mailings etc. Time needed for projects will vary, but none will be sent out with need for ASAP turnaround time. If you are interested please contact [edugan@sbaMass.org](mailto:edugan@sbaMass.org).

MARK YOUR CALENDARS FOR THE  
**SIXTH ANNUAL**  
**sbaMass SUMMER PICNIC**

**SATURDAY, JULY 19, 2008**

**12:30 PM - 4:30 PM**

**AT DANEHY PARK**

**(\*\* ENTRANCE AT 99 SHERMAN STREET, NOT MAIN ENTRANCE \*\*)**

**CAMBRIDGE, MA**

**PARKING LOT AND PICNIC AREA  
NEAR THE OFFICE & RESTROOMS**

**MAP AND DIRECTIONS ON THE NEXT PAGE**

- *Christine Poward*, COO of SBA will join us!
- *Food and Beverages*: Lunch will be provided.
- *Please bring* sunscreen and a lawn chair (if you prefer a chair to the grass!).
- *Picnic Fun*: Activities and surprises for all ages.
- *Other activities* at Danehy Park include a water spray park, playground, and numerous sports fields.



**\*\*\*\* PLEASE RSVP \*\*\*\***

If you know ahead of time that you will be attending, please let us know how many people you expect to bring with you, for planning purposes. Please RSVP to Ellen Dugan at [edugan@sbaMass.org](mailto:edugan@sbaMass.org) or to the sbaMass Voice Mail ((888)-479-1900). If your plans change last minute and you did not RSVP, feel free to join us anyway.

**BY PHONE: (888) 479-1900**



# DIRECTIONS TO sbaMass PICNIC:

## DANEHY PARK SHERMAN STREET ENTRANCE

(99 SHERMAN ST, CAMBRIDGE, MA 02140)

**Please note:** There are lots of different ways to get to Danehy Park, but if you don't know the area, we suggest you use the directions from 95/128. They might be slightly longer than some others, but they are the least confusing!

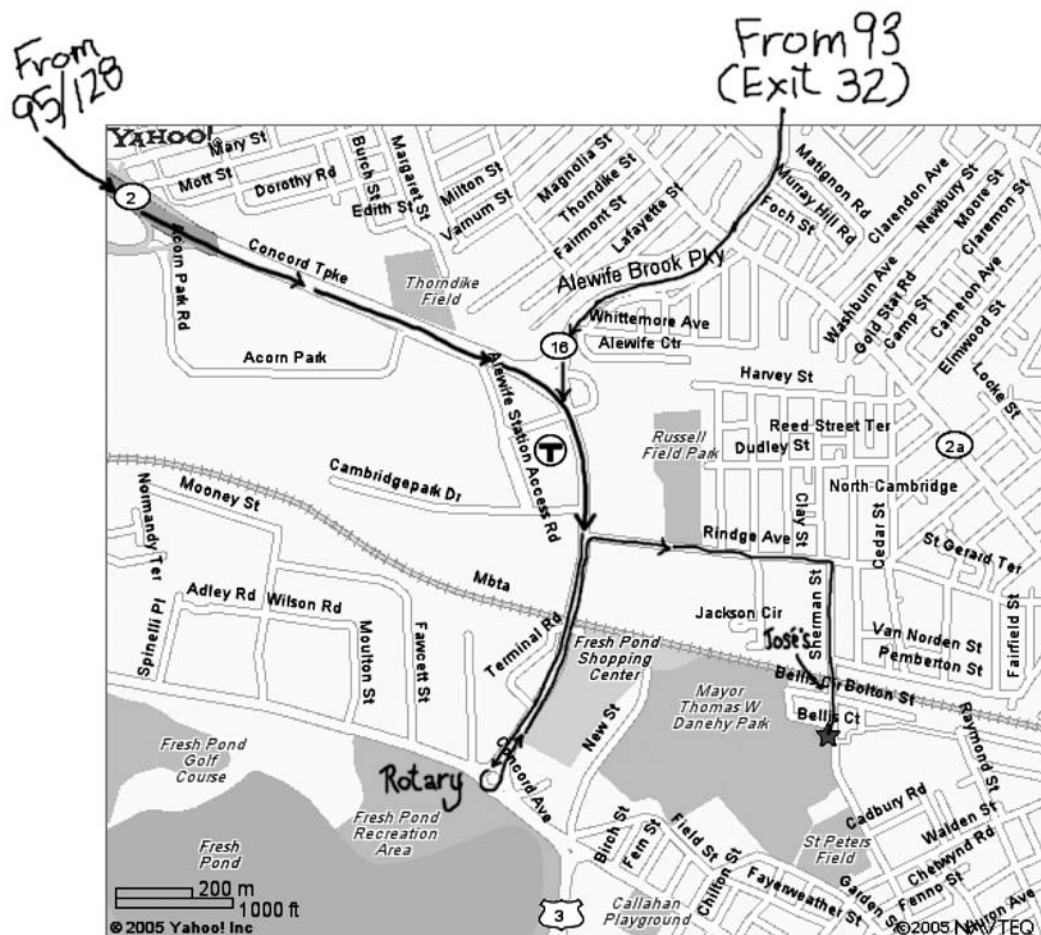
### From Route 95/Route 128 North OR South:

Take Route 2 EAST until it ends/splits. Stay right at this split. You'll see the Alewife (Red Line) T station on your right. Drive past the T station, then follow directions below \*\*.

### From Route 93 North OR South:

Take Exit 32 (Medford Square) and follow signs to Route 16 WEST – a long, winding stretch of road that changes its street name a couple of times. Don't be thrown by that. Stay on Route 16 until you reach its intersection with Route 2 at the Alewife T Station - a total of about 2.5 miles. When you see the T station in front of you, curve left, keeping the T station on your right. Then, follow directions below \*\*.

\*\*You will pass over a railroad bridge and see the Fresh Pond Mall on your left. Keep driving past the Mall to the first rotary (at the Tin Alley Grill). Take the rotary all the way around, and drive *back* – toward Alewife Station and past the Mall again. Go *back* over the railroad bridge, and make an immediate right hand turn onto Rindge Ave. Continue on Rindge Ave for a few blocks, past a cemetery on your right, then turn right on Sherman St. Drive over the railroad tracks and past José's Mexican Restaurant on your right. About 1/10 mile beyond José's is the Danehy Park parking lot on your right. If the lot fills up, there is another lot a little further along Sherman, at a baseball field.



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# New sbaMass Board Members!

**K**athleen Pease is the one of the newest members of the Board of Directors of the Spina Bifida Association of Massachusetts. Kathleen has been a registered nurse since graduating from Johns Hopkins University in 1995. Before that she earned a bachelor's degree from the University of New Hampshire in 1992 in speech and language pathologies, and spent two years in the rehabilitation field. She brings a keen interest in pediatric care to the Board as her entire nursing career has been spent caring for children. She began her career at Johns Hopkins on a pediatric medical/surgical floor, and returned to Boston as quickly as she could to become a pediatric intensive care nurse at Massachusetts General Hospital. After moving to North Andover from Charlestown, she left the ICU to become a pediatric emergency room nurse at North Shore Children's Hospital. She is the mother of three, Owen 7, Bennett 5, and Sadie, soon to be 3 and juggles motherhood, her current job working at a pediatric cardiology clinic, her duties as the PTO co-president at Owen's school and a never ending to-do list.



Kathleen's path to the Board of Directors began five years ago this spring when Kathleen and her husband Ed, welcomed their family's new neighbors, Brian and Cara Packard to their North Andover neighborhood. The Peases were delighted to have neighbors with two young children and both children and parents quickly became friends. This past fall the Packard's encouraged Kathleen to become involved with sbaMass. Kathleen's relationship with the Packards and their daughter Katie, her own experience with her aunt, Santa Fareri, who has Spina Bifida and her career caring for people make Kathleen an excellent fit for Board service. This past spring her aunt successfully had major surgery to untether her spinal cord after an sbaMass member recommended a Boston neurosurgeon who adeptly performed a surgery that many other neurosurgeons had determined to be too difficult. The surgery has changed Santa's life. After joining the Board of Directors this Winter, Kathleen was actively involved in year's golf tournament and has jumped into her service on the board with both feet. Kathleen welcomes the opportunity to serve sbaMass and help make a difference on the Board.

**I**n January, after many years of behind the scenes work, Cara Packard joined the sbaMass Board. For a number of years Cara had the pleasure of helping her husband, Brian, the immediate past sbaMass president, and the other Board members with various projects and programs. She has particularly enjoyed meeting many of our members through the Parents Helping Parents program. Upon Brian's retirement from the Board, Cara felt that it was her turn to be able to give more to the Massachusetts Spina Bifida community. Cara hopes to help the Board continue with the amazing progress it has made over the last several years.



Cara has four children ranging in age from 1 to 10. Their oldest, Katie, has Spina Bifida. Over the years, Katie has taught her parents so much about Spina Bifida and life in general. This knowledge will be very helpful to Cara as a Board member!

Outside of Board activities, Cara enjoys spending time with her family. In her past she practiced law in Massachusetts and New Jersey, but now prefers to mediate the arguments between her own kids. She is a veteran CCD teacher and volunteer in the North Andover schools. Cara graduated with honors from the University of Notre Dame, where she earned both her J.D and B.A degrees. She still loves to spend her Saturdays rooting for the Irish... as well as the Red Sox, Patriots & Celtics.

Cara is looking forward to working with the Board. As a Board member, she hopes that many of you whom she has met along the way through various events and programs will keep in touch, particularly about any new ideas you would like to see implemented.



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# Bits & Pieces

by Hyacinth Bellerose

Maureen is the Adaptive Coordinator at **Piers Park Sailing Center** ([www.piersparksailing.org](http://www.piersparksailing.org)) and an adaptive sailor as well. The programs she offers are as follows:

- For kids/adults with significant cognitive challenge, there is a boat ride program which is often booked by groups.
- After school, for ages 10-17, there is a short spring and fall program.
- During the Summer, for ages 10-17, there is a **free summer sailing program**, generally AM or PM sessions, Fridays, the kids sail to a Boston island.
- Harbor Explorers is a marine biology program for younger kids ages 7-12.
- Outside of children's programs, an adult can learn to sail, including adults with disabilities.

For more info, contact Maureen McKinnon-Tucker at 617-561-6677 or [maureen@piersparksailing.org](mailto:maureen@piersparksailing.org).

**Funding for conferences:** Massachusetts Developmental Disabilities Council may reimburse expenses for individuals with a developmental disability and/or a family member to attend conferences in Massachusetts or other states. Applications must be received and approved prior to the event. For an application and guidelines call 617-770-7676.

**2008 Presidential Election Information** - Go to [www.aapd-dc.org](http://www.aapd-dc.org) and click on Presidential Action Center under NEWS to review candidate's records on disability.

**Funding for Assistive Technology** – click on Fund AT on the left side at [www.massmatch.org](http://www.massmatch.org).

**TOPSoccer** – The Outreach Program for Soccer – is a community-based training and team placement program for young athletes with disabilities. It is organized by state youth soccer association volunteers. The TOPS program is designed to bring the opportunity of learning and playing soccer to any boy or girl with a mental or physical disability. Mass Youth Soccer encourages its organizations to utilize the resources of Mass Youth Soccer to help structure a TOPS program in their area, and it encourages parents of disabled children to contact John Burrill, Executive Director of Mass Youth Soccer. Contact 800-852-8111 x237 or [www.mayouthsoccer.org/pages/95\\_top\\_soccer.cfm](http://www.mayouthsoccer.org/pages/95_top_soccer.cfm).

**A new statewide phone-based Information and Referral service is ready to help - Dial 2-1-1.** Every day, people everywhere in Massachusetts need to find essential health and human services, or community services such as after school programs, a food pantry, or where to secure care for an aging parent. Many face these challenges, but don't always know where to turn for help.

#### **Mass 2-1-1 Call Center Information & Referral Line...**

- Is a **free** and **confidential** call
- Is available **Monday - Friday 8am to 8pm**
- Is an easy to remember **three-digit** telephone
- Connects callers to a trained specialist who can provide information about critical **health and human services** available in your community

See [www.mass211help.org/SmartLocatorPublic\\_1/webforms/home.aspx](http://www.mass211help.org/SmartLocatorPublic_1/webforms/home.aspx).

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## ***MATCHING GIFTS***

Make your contributions go further!

The sbaMass has a list of companies (complete list available at our website: [www.sbaMass.org](http://www.sbaMass.org)) in Massachusetts that provide Matching Gifts for their employees. Check with the personnel department at your place of employment to see how the program works for your company. Review the requirements carefully as each program has its own requirements. Thank you for supporting sbaMass, its programs and services.

***Thank you for your Recent Matching Gifts!***

**Bank of America**



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# Climbing 4 Spina Bifida Update

By John Page - Expedition Leader

**G**reeting friends and supporters! First off, the West Coast Team has started their climbs and completed 2 of their 10 mountains. The first of the West Coast Team summited Mt. Shasta in California April 12, 2008. At 14,162 feet that makes Mt. Shasta the second highest on the West Coast Teams list with only Mt. Rainier at 14,411 feet higher. The second peak was summited on May 3, 2008. Lassen Peak in California stands at 10,457 feet. Summit videos can be seen on our myspace at:

<http://www.myspace.com/climbingforspinabifida>

The East Coast Team has added two climbers to join us as we climb to raise awareness about Spina Bifida. Besides my brother and myself, we are honored to have the following two climbers join us:



**Joe Lesson** from Mohegan Lake New York. Joe attempted to climb Mt. Washington this past winter but was stopped short of the summit due to high winds at over 70 M.P.H. Joe also suffer minor frostbite but attempted to summit twice. He has also designed our summit signs and has been very involved in spreading the word about what we are doing. Joe has become a very close friend and I hope you will all welcome him to the East Coast Team.

Second, we have **Brian LaVoie** from Rochester, New Hampshire. Brian is an experienced hiker in the White Mountains and has also become a close friend A little about him in his own words.



"I enjoy the outdoors and I spend a lot of time hiking in the White Mountains in the Spring, Summer and Fall. In the

Winter I do snow shoeing. I am a member of the Mt. Monadnock-Mt. Sunnapee Greenway Trail Club. I am also a member of Skywarn (Severe Weather Spotter) for the National Weather Service (NWS) and National Oceanic and Atmospheric Administration (NOAA). Along with being a member of those organizations I am also a member of the American Meteorological Society and a member of the booster club for the Manchester Monarchs American Hockey League."

I hope you will also welcome Brian to our team. I feel these two climbers will be a great asset to our team. My team of my brother and I are set to go with our first climbs consisting of Killington, Vermont at 4,235 feet and after a rest day we will be climbing Mt. Mansfield at 4,393 feet.

We will be joining forces with our East Coast Team "B" as soon as we can. They will be starting in the White Mountains in June.

On other notes the Central Team is continuing to get geared up for a fall start so by October all teams will



be climbing and raising awareness about Spina Bifida and how to try and prevent it.

As usual I would like to thank our sponsors for without them there would be no Climbing 4 Spina Bifida. I would also like to take the time to single out some of our sponsors who go above and beyond the call in trying to do all the can to help us with our Expeditions.

- **John Sullivan** at Talus [www.talusoutdoortech.com](http://www.talusoutdoortech.com) John has been a huge help and is a new sponsor who is willing to step up and help out for a cause he believes in. He is a really great guy with a great company so please visit their webpage and say hello!

- **Kristen Bendt** at Katadyn [www.katadyn.com](http://www.katadyn.com)  
Kristen has become a great friend and we hope to meet up with her when we start to climb the peaks in Maine.
- **Sara at Alps Mountaineering** who has just told me she is expecting! So a big congratulations to her and yes she did take her folic acid! Sara is a great person and we value her friendship so please visit them at [www.alpsmountaineering.com](http://www.alpsmountaineering.com)
- **Jason Stadler** at Asolo/Lowe Alpine who has always has gone above and beyond. Please check out our good friends site at [www.asolo-usa.com](http://www.asolo-usa.com) and [www.lowealpine-usa.com](http://www.lowealpine-usa.com)
- **Matt at Lorpen** for going above and beyond to get 10 climbers into the world's best sock! Please visit them at [www.lorpen.com](http://www.lorpen.com)
- **Joe Osborne** at Deuter for becoming a great sponsor and a great friend! Please visit Deuter at [www.deuterusa.com](http://www.deuterusa.com)
- **Kate at Nemo** tents for being not only a great sponsor but a great friend! Please visit Nemo at [www.nemequipment.com](http://www.nemequipment.com)
- **Nate at Snow Peak** [www.snowpeak.com](http://www.snowpeak.com). Nate has become a great sponsor and friend and is an all around great guy so please visit the website.

I have to thank every sponsor we have and so many have become great friends and gone above and beyond. My thank first and foremost go to God for making this happen! I would also like to thank all my team members for believing in my dream.



We also have stickers available for sale on the website or you may email me at [Odessa@comcast.net](mailto:Odessa@comcast.net) if you would like one. They are \$3.00 and the sales of all stickers will be used to help finance gas for all team members. We also have shirts being printed with our C4SB logo and they will be \$15.00 per shirts and should be ready sometime in June. Partial proceeds will be given to our chapter of the SBAA and the rest used for gas.

I hope this latest edition of our news for C4SB finds you all well! Please don't forget to visit us at [www.climbing4spinabifida.org](http://www.climbing4spinabifida.org).

## Items Available

The following are approximately 5 years old, but have only seen light wear.

- A chair. It has an adjustable seat height, adjustable back tilt, cut-outs to allow a small child to grab and pull into the seat. It also comes with a slide on desk-top which can be used and a tilt-able book tray for reading. All pieces are sanded and polyurethaned. For ages approximately 18 months and up
- A wooden stand. This is similar to some that you see for kids in catalogs to reach up to a kitchen counter. This is for children who have the strength to stand already (i.e. there are no straps to hold them vertically), but who need the sides for balance support. It has an adjustable height platform and a step stool for reaching the stand when in is in the "high" position. It has a swing out back with a sliding lock on that side. Appropriate for ages 2-5. It is very heavy to reduce the chance of tipping, but a child should still be supervised when using it.

Please have anyone who is interested contact Christine Rowe ([chrisine@row.cnchost.com](mailto:chrisine@row.cnchost.com)). They should be willing to pick-up in Amherst, NH.

I have a JAZZY1121 power wheel chair. It is gold has all the bells and whistles, reclining back on the chair special foam seat, extra cushion, onboard recharger, one solid wide footrest, adjustable. It turns on a dime and can be taken apart if necessary. It comes with a seat belt, head rest, 5 speed no-flat tires, adjustable in and out arm rests, a horn and lights. I can send you a picture if you give me an address and I can also copy pages of all the stats. I don't have a scanner so I can't email the papers. If you need more information contact Maureen L. McDonald at [moemcd4@aol.com](mailto:moemcd4@aol.com) or (401) 316-5910 (cell).

Also available:

- 1 Rubbermaid Transfer Bench - good condition
- 2 Walkers (no wheels)
- 1 Cane
- Rolls of fabric from a former dressmaking shop

Items are available for pick up in Milford, MA. If you are interested in any or all of the items, contact [edugan@sbaMass.org](mailto:edugan@sbaMass.org).



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# Board Meeting Notes & Updates

By Ellen Dugan

Below is a summary of items that the sbaMass Board has discussed during the last months. Board Meetings are held quarterly in January, April, July and October on the second Tuesday of the month. Meetings are held at 7:00 PM at Panera Bread in Burlington, MA. All constituents are welcome to attend. If you are interested in attending a meeting or have any items to be placed on the agenda, please contact any of us. Agendas will be posted on the sbaMass website [www.sbaMass.org](http://www.sbaMass.org) and the Parents and YAG list serve prior to an upcoming meeting.

- The sbaMass has been scheduled for two Red Sox Community Home Stand outreach opportunities. Representatives of sbaMass will be at the August 15th and September 12th games. The stand is located in the concourse behind Gate A and will be open from 2 hours before the scheduled game through the third inning. If you are attending the game, stop by and say "Hello!".
- The sbaMass would like to welcome three new volunteers to the Programming Committee: **Maura Cox, Jen Fitz-Roy, and Erin Murphy**. Each of these women brings an energy and enthusiasm to the committee along with a commitment to expanding services to parents, tweens and teens. Watch the sbaMass website and your mail for events being planned for the Fall of 2008.
- The sbaMass is currently in the process of expanding its committee structure to better serve the needs of the sbaMass community. Openings are available on the following committees: audit, governance, development, outreach, programming, adult clinic and technology. If you would like more information on these opportunities contact [edugan@sbaMass.org](mailto:edugan@sbaMass.org) or at (888) 479-1900.
- On May 7th and 8th, 2008, sbaMass participated in the Massachusetts Early Intervention Consortium. Much thank you to **Marianne DiBlasi** for co-presenting on the topic "Social and Emotional Development of Children with Physical Limitations" Marianne's perspective on this topic was beneficial to all attending. Thank you Marianne!
- Help sbaMass expand its outreach efforts. We are continually on the look out for opportunities, preferably free or low cost, for outreach. Focus is on both to increasing awareness of Spina Bifida and sbaMass as well as to provide information about the benefits of folic acid. If you would like a sbaMass representative to speak to your child's class, school personnel or business, contact [edugan@sbaMass.org](mailto:edugan@sbaMass.org) or at (888) 479-1900. In addition if you are aware of events in your local community i.e.: health fairs, please contact us. The sbaMass can broaden our outreach efforts if we increase the participation of members of the sbaMass community. If the event is in your community, sbaMass can provide the items for outreach, if you or family members can operate the table.

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## The sbaMass ANNUAL BENEFITS PROGRAM \$500 for 2008

For the **OFFICIAL POSTING and/or APPLICATION (both posted on [www.sbaMass.org](http://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](mailto:edugan@sbaMass.org) or fax (978) 926-7700 or leave the information and request in a phone message at (888) 479-1900.

# Contacts

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

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

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Also try World Arnold Chiari Malformation Association at

<http://www.presenter.com/~wacma/>

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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](mailto:edugan@sbaMass.org)*



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