

# MSBA NEWS

A Publication of the  
Massachusetts Spina Bifida Association

Member, Spina Bifida Association of America



## Ain't No Time for the Summer Time Blues!

by Ginny Briggs

The MSBA's annual summer picnic held on Saturday, July 15th, was a smashing success this year, attended by 70 of our members, their friends and family. For the second year in a row, Danehy Park in Cambridge served as our site for this splendid event. We were able to secure the perfect location, right in front of the playground and sprinklers (called "the Wheeler Water Garden frog pond"). The kids had a blast getting nice and wet on this hot, July day, then having fun in the playground as well as creating things at the arts and crafts table. The adults had fun too, chatting with old and new friends and enjoying the great foods donated by Hannaford's of Waltham, Whole Foods of Cambridge and Polar Beverages. Brandon Shanks MC'd a scavenger hunt where participants were required to ask other picnic attendees things like "what is your middle initial?" and "can you think of a song with the word Saturday in the title?". Completed questionnaires were put into a box and the winner's name was drawn. This year's winner was Chrissy Briggs of Attleboro who won a \$50 gift certificate to Legal Seafoods.

The event wrapped up late in the afternoon as the weather started to cool down, and both friends and families headed home after a wonderful day outside. I'll look forward to next year's picnic and hope to see even more folks from our MSBA community join us!



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# Summer in the City!

Hot Time!



# PICNIC



# Summer Picnic



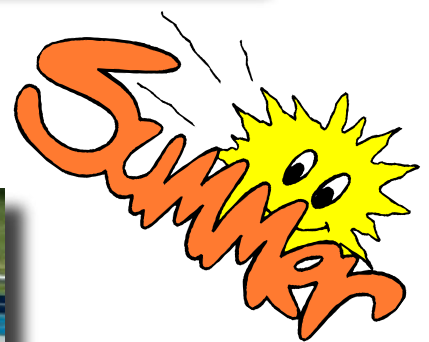
## Danehy Park



**Thank You!**



- ☺ Hannafords of Waltham
- ☺ Whole Foods of Cambridge
- ☺ Polar Beverages
- ☺ Brigham's



# 2006 Jean Driscoll Scholarship Recipient - Marcus Stacy

by Ellen Dugan

In 2002, when the MSBA was applying to become an official charity of the Boston Marathon, one of our greatest promoters and sources of support was Jean Driscoll. An adult with spina bifida, Jean holds the record for winning the Boston Marathon more times than any other individual. She reached the finish line ahead of her competitors a total of eight times, in the wheelchair division of the race. During the lead up to Team MSBA's first year in the Marathon, Jean came to Boston to tell the story of her efforts. A wonderful motivational speaker and a genuinely kind person, she made everyone in the room feel like they could do anything. In thanks for the help and encouragement she offered both to our Marathon Team and to the members of the MSBA, the Board established an annual scholarship in her name. The Certificate given to the person who wins the award each year reads as follows:



Jean Driscoll

*"In appreciation for her support, inspiration and dedication to the spina bifida community in Massachusetts, the Board of Directors and members of the Massachusetts Spina Bifida Association created the Jean Driscoll Scholarship. Presented annually, this \$1,000 award is to be used by the recipient for educational, athletic, developmental or assistive programs." Through this award, we honor "the individual with spina bifida in Massachusetts who best demonstrates the character and determination of the scholarship's namesake."*

The Board reviewed a number of very impressive applications for this year's scholarship, and it was hard to choose just one recipient. Our thanks and best wishes go out to all who applied. In the end, we selected Marcus Stacy.

## *Congratulations Marcus!*

Marcus is an adult with spina bifida. He and his family reside in Boston where he graduated from Boston Latin and will be a senior at the University of Rhode Island in September. He resides on campus during the school year and is an English major. He plans on teaching after graduation. Marcus' passion is acting and directing and he has several original works to his name. He has just completed his first full length screen play which he hopes to film in the future.



Marcus' dad accepts the award in his absence

During the summer months Marcus is the head of the drama department at a summer camp in New Hampshire. During the summer of 2001 Marcus participated in the Counselor in Training Program at the camp. When his CIT Group was planning the traditional hike up Mount Washington, it was assumed Marcus would pass or get a ride to the top of the mountain. Marcus completed the hike with his group, surprising even himself.

He continues to challenge himself both physically and intellectually and he wrote in his application: "One in my position could very easily sit around doing nothing, obsessed with the idea that he has been given a bum deal, allowing thoughts of what he can't do to consume him. But life itself is a set of obstacles, and the fact is that people like me are faced with a unique subset. We must do everything we can to conquer those obstacles and if they can not be conquered, we must embrace them and integrate them into our lives in a positive and proactive way."

Marcus was not able to attend the MSBA Picnic as he is working at the summer camp, but his dad, Mark Stacy, ably stood in for him accepting the Jean Driscoll Scholarship on his behalf. Congratulations Marcus, and good luck in the fall. We are all looking forward to your first screen play.



# 2006 SBAA Annual Conference Report

## Atlanta, Georgia

by Ginny Briggs

If you didn't make it to the Annual SBAA Conference this year, you missed a particularly good one. The conference is a great place to learn and share ideas with other people and families affected by spina bifida (s.b.). This year, our national office (SBAA) did a particularly good job in working with all the SBA board members who attended and in scheduling some very interesting speakers who presented over the course of three days.

It all started with Group Member Day (Saturday/Sunday), a session designed for SBA board members. The day was spent sharing ideas about how to more effectively operate our individual state SBA's and building a "vision" for our future. It was great to hear how other states are doing and how we can learn from each other to better serve our members.

The first official night, Sunday, began with the usual Opening Night Reception, sponsored by the SBAA. There was live music along with several clowns circulating through the crowd, entertaining all ages. All the medical supply company vendors were there, showing everyone the latest technology and there was wine, beer and a great buffet of Mexican food. The whole event is not to be missed!

The Plenary Session began bright and early Monday morning. The topic of interest this year concerned how to better care for people aging with s.b. Leaders in the areas of urologic care, orthopedics, neurosurgery and psychological health each gave short presen-

tations addressing the adult s.b. population. Among the speakers was Dr. Earl Cheng, a pediatric urologist from Children's Memorial Hospital in Chicago. Dr. Cheng is one of the best speakers I've heard and has attended and presented at the last three conferences I have been to. I always look forward to hearing about the latest in research and the kinds of issues a urologist faces when treating the s.b. population.

Beginning Monday afternoon and ending late Wednesday, there were presentations, workshops and chat groups scheduled throughout each day. The topics ranged from wheelchair fitting, dating and employment, to tethering, self-catheterization and learning disabilities. The most popular sessions are called "Ask The Doctor". These sessions are dedicated to allowing anyone to ask a specialist in one area (urology, orthopedics or neurosurgery) any question they wish that is related to that area of specialty.

One of the highlights of the week was the Awards Luncheon on Wednesday afternoon. Someone near and dear to our hearts was the keynote speaker this year, Jean Driscoll. She gave a very inspiring talk about her experience growing up with spina bifida and her climb to success, winning the Boston Marathon a record eight times over her career. Her descriptions of both physical and emotional hurdles in training to finish such a long race were touching and also, at times, quite funny. She's a wonderful speaker and it was a pleasure listening to her story. Many of her experiences are described in her recently published book, "Determined To Win".

During the luncheon, several awards were given to local chapters



**Jazz musicians entertain the crowd at the Opening Night Reception**



**Eight-year old Abigail Branson (center) from Madison, MS and five-year old Grace Briggs-Neal from Marlboro, MA have a conversation with a clown at Sunday night's Opening Reception**



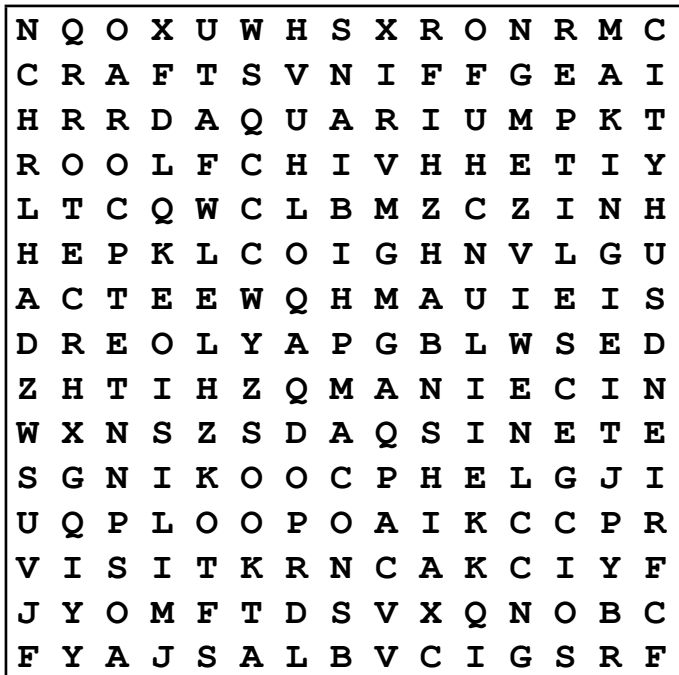
**Ginny Briggs and Hyacinth Bellerose of the MSBA Board accept the first place award on behalf of MSBA for "Outstanding Website". (L to R) Ginny Briggs (MSBA), Doug Sorocco (National), Hyacinth Bellerose (MSBA) and Tim Yoder (National)**

Please see **CONFERENCE / 18**

# Kids Corner



## SBA Kid's Camp Word Search



Find the words below in the Word Search puzzle!

AQUARIUM	HOCKEY
AMPHIBIANS	HOTEL
ARTS	LUNCH
BOWLING	MAKING
CITY	NEW
CLIMBING	PIZZA
COOKING	POOL
CRAFTS	REPTILES
CYCLING	ROCK
FLOOR	SCIENCE
FRIENDS	SPORTS
HAND	VISIT
	WHEELCHAIR



## Fun Facts



An ant can lift 50 times it's own weight!  
Go ants!



A flea can jump 350 times  
its body length!



A group of kangaroos is  
called a mob!



What's better  
than a talking  
dog?

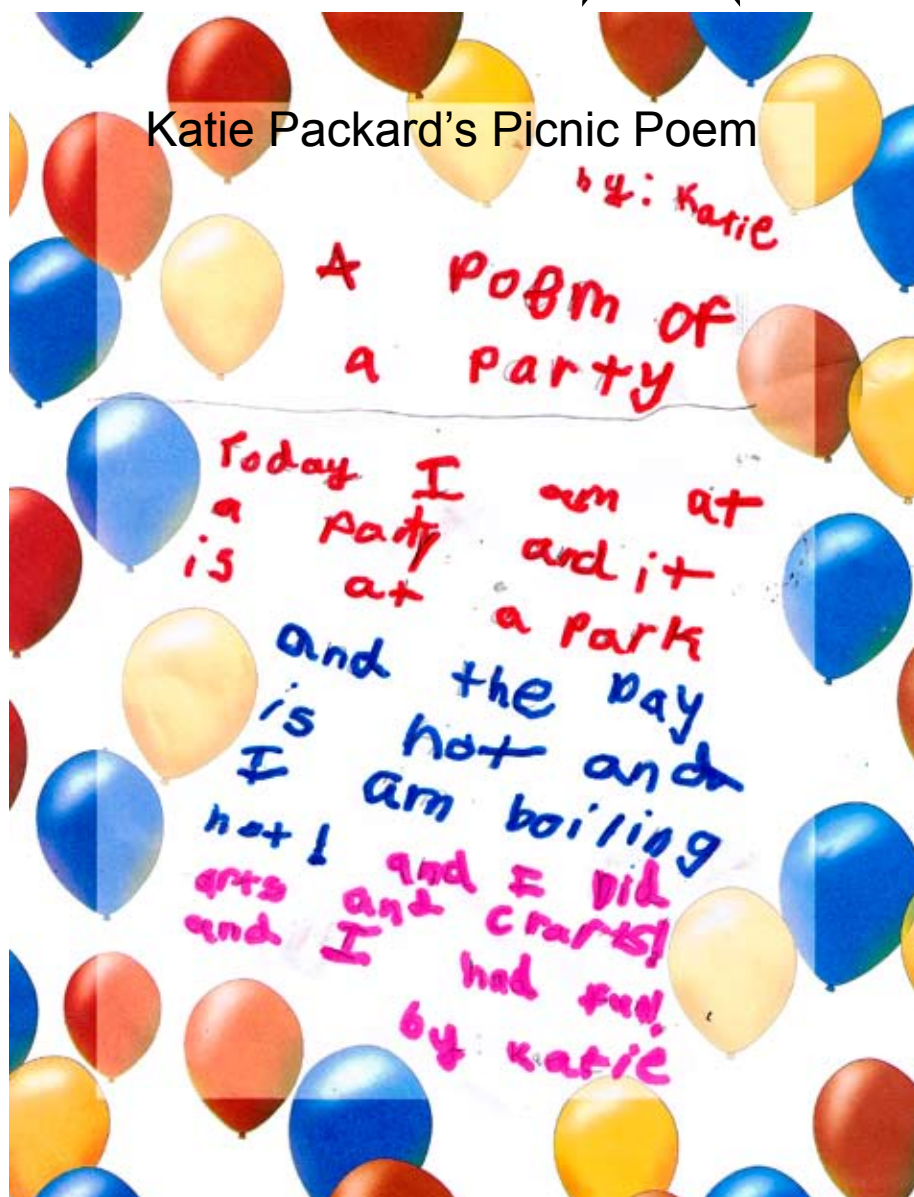
A spelling bee!



Hey Kids!



Katie Packard's Picnic Poem



Got a joke, story  
or cool fact that you'd  
like to share? Ask your  
parents to send it to the  
editor and we'll try to put  
it in the next newsletter!



# MSBA Youth and Adults Group

by Jen Kuhar

It has been another busy summer for the MSBA Youth and Adults Group. Approximately 10 of us traveled to Atlanta to attend the SBA's Annual Conference. This year's conference focused on adults with an entire day dedicated to issues faced by adults living with spina bifida. Discussions included independence, social networking, fitness and medical issues. Folks shared ideas and experiences about achieving independence, creating support systems, socializing and staying fit and healthy. Other sessions included topics such as transitioning to adulthood, non-verbal learning disabilities, tethered cord, urological issues and dating and relationships. "Adult Night Out" was a casino night where folks tried their luck at various casino games including Black Jack, Craps, and Texas Hold 'Em. A great time was had by all. Next year's conference will be in Louisville, Kentucky June 24-27, 2007 at the Galt House. If you have never been to conference, we strongly urge you to go next year. It is a great opportunity to learn more about spina bifida and meet others who are also experiencing the same issues as you are. Once you go to one conference, you will be hooked, so start planning now!

Back here in Massachusetts, the MSBAYA Planning Committee has been busy. We hosted a Parent Discussion Day in June. It was a day where parents could discuss issues they face and share information with others. The MSBAYA Planning Committee and Jen Fitz-Roy facilitated the day.

Your MSBAYA Planning Committee is organizing the Lunch and Learn being held on Saturday, October 21, 2006 at the Lexington Library. Watch for more details coming soon. And of course, don't forget to join us at the Holiday Party on December 3, 2006 at the Hampton Inn Natick.

Would you like to see activities closer to you? Contact your Regional Representative and let them know. Their contact information is inside this newsletter. With the help of our Regional Representatives, the MSBA will be making an effort to bring programming closer to everyone. But, in order to reach you, we need to hear from you. See you soon!

## Upcoming MSBAYA Events

Date	Event	Location
Sept. 18	MSBAYA Committee Meeting - 7 pm	Panera Bread, Waltham, MA
October 21	MSBAYA Lunch and Learn - Details TBD	Lexington Library, Lexington, MA
December 3	MSBA Holiday Party -12:30 pm	Hampton Inn, Natick, MA

MSBA Youth and Adults Group Committee	
<b>Robyn Hand</b> Email: rlhand97@aim.com	<b>Lindsay Meuse</b> Email: Lmeuse124@aol.com
<b>Jen Kuhar</b> Email: jkuhar@msbaweb.org	<b>Aimee &amp; Brandon Shanks</b> Email: orchid03@yahoo.com
<b>Tree-ci Spillane</b> Email: mtspillane@comcast.net	



## What Happens When We Go To The Emergency Department?

It is not uncommon for a person with spina bifida (SB) to experience many health concerns, including urinary tract infections, shunt problems, surgeries and more. Along with these various threats to health comes a need for frequent visits to the doctor and, at times, the emergency room. And, when a person with SB goes to the emergency room with symptoms such as headaches, vomiting or abdominal pain, the cause is much more likely to be life threatening than for a person without.

A study recently published in the 2006 Journal of Emergency Medicine examined the reasons people with SB visit the emergency room as well as their diagnoses.

The study evaluated 125 patients with SB who visited the emergency department 258 times. In total, there were 408 complaints made by these patients, the most common of which were related to gastrointestinal functions (including vomiting, nausea and abdominal pain). Neurological complaints were also common and included headaches, seizure and mental status changes. Other areas causing distress were related to swelling and pain in bones, joints and skin; breathing difficulties; urinary tract problems; chest pain; and psychiatric issues (such as depression, panic attacks and thoughts of suicide).

UTI's and cellulitis (infection under the skin) were the two most common diagnoses for patients complaining of fever. Most of the patients who had experienced vomiting were also diagnosed with either a UTI or dehydration. Roughly one-third of all the patients complained of headaches, half of which were determined to be symptomatic of shunt malfunctions, seizures or UTI. Interestingly, for almost half of the patients presenting abdominal pain symptoms, the most common diagnosis was also a UTI. Not surprisingly, UTI's were also found to be responsible for the majority of urinary tract complaints. Among the diagnoses for patients presenting changes in their mental status were: one case of a UTI, seizures, shunt malfunctions and dehydration. Lastly, more than one-third of patients complaining of musculoskeletal (bone and muscle) pain were determined to have fractures.

As a result of the findings of this study, the authors have made several recommendations:

1) Only 34% of patients who had UTI's showed the usual symptoms. This means that 66% (two-thirds) of patients who had UTI's received delayed care, which could have caused some damage to their kidneys and urinary tracts. Therefore, it is essential that UTI's be of primary consideration when a person with SB is seen in the emergency room, even for symptoms not normally associated with UTI.

2) Of the 12 study patients who were determined to have shunt malfunctions, 10 presented with symptoms of mental status changes and/or seizures, while two complained of headaches alone. Since shunt complications can cause irreversible damage and could be life-threatening, cases where shunt complications are suspected should always be evaluated by a neurosurgeon for pressure changes and presence of infection.

3) In the study, only one of the fractures was determined to be caused by significant trauma. The remaining fractures were likely the result of trauma that the patient was not aware of. Since people with SB often have limited feeling in their legs, it is possible that a symptom of swelling or pain could be as serious as a bone fracture, rather than just a bruise. Emergency room healthcare providers should be made aware of the potential for a fracture so that it is not missed and left untreated.

The findings of this study give the SB community some important things to think about when going to the doctor's office or the emergency room. It is important to talk about the common problems associated with SB, including UTI's, fractures and shunt infections and malfunctions. Furthermore, it is extremely important to explore these diagnoses as possibilities, even when the presented symptoms are not typical of said problems.

REFERENCE: Caterino JM, Scheatzle MD, et al. Descriptive analysis of 258 emergency department visits by spina bifida patients. Journal of Emergency Medicine, 2006. v. 31 (1), p.17-22.

**RESEARCH DISCLAIMER:** The contents of this article are for informational purposes only and are not intended to replace medical diagnosis and treatment. The research provided is for educational and information purposes only. The reference to these research studies does not present an endorsement or recommendation of such studies. There are many other studies, which for various nondiscriminatory reasons, are not presented in this publication. The MSBA does not diagnose medical conditions, offer medical advice or endorse specific products, services, procedures or companies. The MSBA makes no representations or warranties with respect to quality, efficacy, safety, reliability, qualifications, or desirability of the studies or researchers, and specifically disclaims any other warranties, express or implied. If you would like to know if the information in the article is appropriate for you, consult your medical doctor.

# Bits & Pieces

....from websites to singles events to quick tips...

by Hyacinth Bellerose

**H**ave trouble remembering birthdays???? Check out [www.birthdayalarm.com](http://www.birthdayalarm.com). Request that friends and family enter their own birthdays, (no year necessary!) or input the information yourself. You will receive email reminders of each person's special day! Other events can be added as well.

**S**BA Conference 2007 will be in Louisville, Kentucky. It's either 15-16 hours by car, or 4-5 hours by plane (one stop) for under \$300.00! Louisville should be one of the less expensive sites, so it would be a great year to experience Conference!

**W**hether it is how to best present a writing assignment or how to ask a classmate to a dance, the authors of Nonverbal Learning Disabilities: A Guide to School Success share their experiences as three professionals who have taken the time to listen to and learn from their students. Check out [www.mapleleafcenter.com](http://www.mapleleafcenter.com) or call 1-802-446-3601 for more info on NVLD books and seminars.

**E**-newsletters you won't want to delete: From the New York Times owned [www.about.com](http://www.about.com), available for free at <http://clk.about.com/?zi=4/XR>. Use their website as a research tool to find the applicable articles, reviews and resources you need on a particular subject. I've signed up for Traveling with Kids and Education, but they also have categories such as Needlecraft, Electronics and Pets, to name a just a few. Subscribe to the newsletter that best fits your needs. They have done all the research for you.

And, if you don't want the newsletter any more, it is very simple to unsubscribe.

**W**weekly, accessible outdoor adventures. From Hopkinton to Northampton to Concord and beyond, check out [www.mass.gov/dcr/universal\\_access](http://www.mass.gov/dcr/universal_access) to receive DCR's newsletter listing a summer full of activities from kayaking to biking to camping and more. (Phone 1-413-545-5353). EXPLORE!

**D**isabilities and nursing: The website [www.exceptional-nurse.com](http://www.exceptional-nurse.com) focuses mainly on nurses with disabilities and nurses helping people with disabilities. However, there are also links to other legal, book and website resources that would be helpful to parents of and individuals with disabilities. Take a look around this site for a more medically minded view of the disabilities issue, or pass the address along for your care providers to browse today.

**N**LD: A Guide to School Success; conferences Newton, MA 10/16/06 and Nashua, NH 11/13/06; for more info, contact [www.mapleleafcenter.com](http://www.mapleleafcenter.com) or call 802-446-3601.

REMINDER: If you do not have web access, leave a message at our toll-free 800 phone number stating (1) the item(s) under Bits and Pieces for which you would like more information; (2) your name; (3) your mailing address; (4) your phone number. The MSBA will print out the information or story and send it to you.

Please submit Bits and Pieces to Hyacinth Bellerose (contact info inside back cover).

## 3rd Annual Education Fair - September 28th

**T**he Children's Hospital Boston is holding its 3rd Annual Education Fair for patients and families on Thursday, September 28, 2006. It will be from 4:00-6:30 p.m. in the Patient Entertainment Center at CHB. The fair starts with two keynote speakers, both former patients of Children's. Following the speakers, there will be time to visit the participating schools. This will allow an opportunity to get information on admissions, handicap accessibility, learning disability services

and other services that could help prospective students be successful. Colleges, universities, trade schools and GED programs from all over New England have been invited to participate. Last year's fair hosted 30 programs, plus representatives from both federal and Mass. financial aid programs. For additional information contact Miranda Guardiani at 617-355-6561 or via email at [miranda.guardiani@childrens.harvard.edu](mailto:miranda.guardiani@childrens.harvard.edu).





Thousands of runners stream around the picturesque Nobska Point just past the one mile mark

# Team MSBA Runs in the Falmouth Road Race!

by Brian Packard

**15** members of Team MSBA competed in the Falmouth Road Race on August 13th to raise funds and awareness for our cause. The runners each wore our newly-designed and extremely bright running singlet, which could not be missed by the throngs of people along the 7-mile course. Donations are still coming in, but we expect that the fundraising effort will far exceed our goals. Congratulations and thanks to each runner! If you are interested in becoming a member of Team MSBA, the official running team of the Massachusetts Spina Bifida Association, please contact Brian Packard at [bpackard@msbaweb.org](mailto:bpackard@msbaweb.org).

## Advocacy News

Become an advocate now! Ask family and friends to do so as well.

### Congressional Spina Bifida Caucus

On May 15, 2003, Congressman Chris Smith (R-New Jersey), along with his colleague and SBA champion, Congressman Bart Stupak (D-Michigan), announced in a letter to fellow Members the formation of the Spina Bifida Caucus.

Caucuses direct focus and attention to specific issues. They are formally organized and recognized entities formed by Congress members. Separate and distinct from congressional committees, caucuses are neither restricted in membership nor tied to the political makeup in the Congress. Any member can join.

Although there are 50 members of the Spina Bifida Caucus, currently Massachusetts, New Hampshire and Vermont do not have congressional representatives who have signed on.

Support SBAA's advocacy efforts. Please take a few moments to contact your congressional representative(s) urging them to sign onto this caucus. If you are unsure of who your representative(s) may be, the Spina Bifida Association can help. Simply visit our site, [www.sbaa.org](http://www.sbaa.org) and click the Advocacy Section link.

### Increase Funding for the National Spina Bifida Program

We are now considering crucial budget decisions. Let your voice be heard! Which issues are of importance to people with spina bifida? You can make a real difference!

Help make spina bifida a national priority by taking action. ACT NOW! Ensure that the National Spina Bifida Program receives \$6 million in funding for FY 2007 so that it can continue its important work on behalf of the Spina Bifida Community!

The CDC's National Spina Bifida Program strengthens the federal government's commitment to spina bifida. It supports important approaches, offering promise of improved quality-of-life and increased primary prevention of Spina Bifida. However, despite its excellent work, unmet needs remain, due to limited resources.

To help, visit [www.sbaa.org](http://www.sbaa.org) and click ACT NOW! on the home page.

# Holiday Party Announcement!



## THE HOLIDAY PARTY PLANS ARE IN FULL SWING AND WE NEED YOU!!

**T**hat's right, the MSBA is already busy planning this year's Holiday Party, to be held on Sunday, December 3rd at the Hampton Inn Natick. Last year's party was a big success, thanks to the dozen volunteers who worked feverishly behind the scenes to ensure that everything went off without a hitch. WE NEED YOUR HELP AGAIN AND THAT OF OTHERS THIS YEAR! To get involved, please contact Jen Kuhar at [jkuhar@msbaweb.org](mailto:jkuhar@msbaweb.org), or leave her a message

on the MSBA's voicemail.

Below is a partial list of how you can help:

- Assist with reminder phone calls
- Donate – items could include gifts for kids, craft supplies, food, items for prizes and raffles, and more.
- Shop for gifts
- Wrap gifts
- Assist with various tasks on the day of the party

## Letter from the President

by Brian Packard

**I** hope you are enjoying the summer with friends, family, beaches and barbecues. Thanks for joining us on July 15th at Danehy Park in Cambridge for the annual MSBA Summer Picnic. We had a great turnout, a huge spread of food and lots of fun. It didn't hurt that the weather was absolutely perfect.

It was also great to see some of you in late June in Atlanta for the Spina Bifida Association Annual Conference. As always, the conference was packed with fun activities, informative presentations and the reunion of friends from around the country. This year during Group Member Days, SBA reviewed the progress of the Group Member Task Force, a committee formed to create a vision for field operations nationwide. The task force reviewed a set of draft recommendations for Group Member feedback, including proposals for Board composition, financial management and communications/branding. This was the first of many meetings the task force will hold with Group Member leaders over the coming months. Their hope is to come to broad consensus on a complete set of requirements for chapter operations in the future, and we look forward to helping SBA achieve that goal.

You may have noticed that MSBA News has taken on a cleaner, more simplified look. As promised in the spring, we are focused on meeting the needs of our members, some of whom have told us to improve the readability of our newsletter. Thanks to our new editor, Pete Jablonski, for his help in this effort. I would also like to officially welcome Pete to the MSBA Board of Directors. Pete is a

senior scientist at a technology firm in Waltham, and has both a Ph.D. and postdoctoral fellowship in microbiology. Most importantly, he brings great energy and technical expertise to the MSBA, as shown by the award-winning MSBAweb.org website he created for us. Please join me in welcoming Pete.

Team MSBA had a triumphant return on August 13th, with 15 teammates competing in the famous Falmouth Road Race. Runners enjoyed a cooler-than-normal day and the sun shone brightly on their orange-and-blue flamed running singlets. No one in the crowd of thousands could miss the MSBA logo! I would like to thank each member of the team for their dedication to training, fund-raising and building awareness for our cause.

Lastly, I would like to take a moment to thank the members of the MSBA Youth and Adults Committee (MSBAYA) for all their hard work over the last year. Robyn Hand, Jen Kuhar, Lindsay Meuse, Tree-ci Spillane and Aimee and Brandon Shanks have done an outstanding job organizing programs for an ever-growing group of members. This group is now 160 members strong, and meets regularly for social and educational events. The next major program will be a Lunch and Learn on October 21st at the Lexington library. Speakers are still being finalized and will be announced via the website and MSBAYA Yahoo! Group.

Until then, enjoy the rest of the summer. I wish you health and happiness.

Brian Packard



## Question of the Quarter

The MSBA Board is seeking meaningful feedback on a number of issues that may affect you. If you'd like to participate, either fill out the form below and send it to the MSBA address listed on the Contact page (page 19) or online at [www.msbweb.org](http://www.msbweb.org).

All information is kept confidential and only overall responses may be reported in the next newsletter or online.

### This Quarter's Question:

*Travel to the National Spina Bifida Conference is considered by many members. What reason(s) do you have for not attending the conference?*

- |   |   |
|---|---|
| <input type="checkbox"/> Too busy             | <input type="checkbox"/> Topics Presented don't interest me |
| <input type="checkbox"/> Don't like to travel | <input type="checkbox"/> Don't know about the conference    |
| <input type="checkbox"/> Too expensive        | <input type="checkbox"/> Other _____                        |
| <input type="checkbox"/> Accessibility issues |   |



## Board Meeting Notes

by Jen Kuhar

Below is a summary of what the MSBA Board has discussed over the past few months. Board meetings are held on the first Monday of each month at 7:00PM at the Lahey Clinic in Burlington. All members are welcome to attend. If you are interested in attending a meeting or have any issues or concerns to be brought up at a meeting, please contact any one of us.

- The Second Annual MSBA Golf Tournament raised approximately \$11,000. These funds will assist the MSBA to continue and expand its programs. The 2007 MSBA Golf Tournament is scheduled for May 7, 2007 at Sky Meadow Country Club in Nashua, NH. Mark your calendars now!
- Pete Jablonski has joined the MSBA Board of Directors. He is the new Editor of MSBA News and will remain Web Master of [www.msbaweb.org](http://www.msbaweb.org). Amy Blanchard will assist Pete by editing the articles submitted.
- The MSBA's Web site, [www.msbaweb.org](http://www.msbaweb.org) won first place at the SBA Conference in Atlanta, GA in June. A big congratulations and thanks go out to Pete!
- Ellen has compiled a binder of resources for new parents entitled "Getting Going". This is an excellent resource for new parents of children with spina bifida.
- The MSBA is a registered non-profit organization with the Lexington Library. This allows us to use their meeting space, when available.
- In June, Hyci and Ellen met with the Myelo Clinic at Children's Hospital Boston to update them on recent MSBA activities. Children's Hospital is collaborating with other organizations to develop Centers for Excellence for individuals with spina bifida. They discussed ways the MSBA could assist with this project. The MSBA and Boston Children's Hospital will continue to meet on a regular basis.

# MSBA Membership Information

**T**he Massachusetts Spina Bifida Association is a nonprofit corporation founded in 1971 by a group of concerned parents of children with spina bifida. A member of the Spina Bifida Association of America, the MSBA is dedicated to enhancing the lives of people in Massachusetts affected by spina bifida, by providing a community of support, advocacy and education.



## What are the benefits of becoming a member?

- A strong Youth and Adults Group
- Fundraising
- An extensive Benefits Program
- Social Events
- A developing Parents Helping Parents program
- A Parent's Chat Group
- Online Discussion Groups
- A Lending Library

Qualified Applicants also receive:

- the award-winning MSBA quarterly newsletter
- the SBAA's newsletter Insights
- may receive other MSBA benefits

## Who is a "Qualified Applicant"?

- A person with Spina Bifida who resides in Massachusetts or a New England state that does not have it's own SBAA-affiliated entity.
- Benefits are available to only one person per family unless there is more than one person with Spina Bifida in that family.

## What does it cost?

There is NO membership fee, but tax-deductible donations are appreciated!

## How do I join?

To become a member, either visit our web site and fill out the online form or fill out the application on the next page, and return it to:

**MSBA Membership**  
733 Turnpike Street, #282  
North Andover, MA 01845

## How do I make changes to my membership?

- Please send us an update whenever there are any changes to your information, including your email address!
- Members can also update their information by sending an email to [mneal@msbaweb.org](mailto:mneal@msbaweb.org).
- The MSBA Board is open to suggestions from members as to how we can better serve our community. Please watch this newsletter and our Web site at [www.msbaweb.org](http://www.msbaweb.org) for ongoing events and programs.





# MSBA Membership Application / Update Form

Please fill out the following information as applicable to your situation:

**Type of Membership:**

- ☐ Qualified Applicant (Teen or Adult with spina bifida)
- ☐ Family (Parent(s) of Child with spina bifida)
- ☐ Associate (Interested Friend or Family Member)
- ☐ Medical Professional

Please check one:

- ☐ NEW Membership
- ☐ Renewal

**Name of person with spina bifida:** \_\_\_\_\_

**Date of Birth:** \_\_\_\_\_

(\*Important. This info helps us provide appropriate support to members of different ages): \_\_\_\_\_

**Spouse / Partner / Other Family Members :** \_\_\_\_\_

**Member Name** (if different from person with s.b.): \_\_\_\_\_

**Organization and Title** (if appropriate): \_\_\_\_\_

**Street Address:** \_\_\_\_\_

**City, State, Zip:** \_\_\_\_\_

**Telephone:** \_\_\_\_\_

**Email:** \_\_\_\_\_

**Please contact me about becoming a volunteer** \_\_\_\_\_

**Optional tax deductible donation \$** \_\_\_\_\_

**Other information you would like us to know** (siblings, level of s.b. lesion, suggestions, etc...):

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**MSBA Membership  
733 Turnpike Street #282  
North Andover, MA 01845**

# MSBA Benefits Program

**Qualified Applicants\***  
**of the MSBA are eligible for**  
**significant financial help each**  
**year through our**  
**Benefits Programs.**

## **Annual Benefits Program**

A Qualified Applicant (see Membership information on pg. 14 of this issue) is entitled to \$500 per year to be used to enhance independence, increase mobility or otherwise improve his/her life as it is affected by spina bifida. The funds may be used for braces, crutches, canes, catheters and continence supplies, summer camp, assistive technology, educational items or other similar expenses.

## **How do I Apply for Benefits?**

A Benefits Application must be submitted, in writing, to the MSBA Benefits Coordinator (Ellen Dugan), by the Qualified Applicant or their parent or guardian via postal mail or e-mail. The application will be reviewed for approval at the following month's Board of Directors meeting.

## **How do I receive Benefits funds?**

Once the application has been approved, there are two ways for a Qualified Applicant to receive Benefits funds:1.

**Reimbursement:** The Qualified Applicant may present a receipt showing payment of an eligible expense already incurred. Once this receipt is received and reviewed, the MSBA will write a check to be paid to the Qualified Applicant or their parent or guardian, as reimbursement.

OR

2. **Direct Pay:** A bill or invoice for the eligible expense to be incurred may be presented to the Board of Directors in advance. In this case, the MSBA will write a check directly to the benefit provider or vendor for the expense in question.

**Name:** \_\_\_\_\_

**Street Address:** \_\_\_\_\_

**City, State, Zip:** \_\_\_\_\_

\_\_\_\_ **MSBA Annual Benefit** **\$500**  
Get \$500 Annual Benefit just by applying.\*

Please tear out this  
application form  
and return it to:

**Ellen Dugan**  
**MSBA Benefits Coordinator**  
**733 Turnpike Street #282**  
**North Andover, MA 01845**

Requests outside of this scope will be reviewed on an individual basis.  
Benefits Program payments can take up to 30 days to process. Please be patient.  
The MSBA reserves the right to revise this policy in accordance with the changing financial position of the MSBA.

\* Please note: Membership in the MSBA is not required to receive Benefits.

## MSBAYA Planning Committee Needs You!

The MSBAYA Planning Committee is always looking for volunteers to help plan events and keep the group hopping. The Committee meets on the third Monday of every other month. If you would like to get involved, or join the MSBAYA online Yahoo!Group, please contact any of the Committee members listed on page 8 of this newsletter.



## Donations and Special Contributions

The MSBA would like to thank everyone who has generously donated or contributed recently. Your support is greatly appreciated!

Thanks to all who supported runners in the:

- ◆ Boston Marathon
- ◆ Chicago Marathon
- ◆ Falmouth Road Race

Special thanks to the companies donating to the MSBA Summer Picnic:

- ◆ Hannaford's Market of Waltham
- ◆ Whole Foods of Cambridge
- ◆ Polar Beverages
- ◆ Brigham's

*At this time we're evaluating the privacy issues surrounding publishing contributor's names and have chosen to print only corporate sponsors and not individual names until a policy is in place. If you would like your name published, please contact Ellen Dugan at the MSBA phone number listed on page 19 or at [edugan@msbaweb.org](mailto:edugan@msbaweb.org).*

## Would You Like to See MSBA Activities in Your Local Area?

**Contact your  
Regional  
Representative  
today!**  
(see Contacts on  
page 19)  
**to let them know!**

**We want to hear  
from you!**



*Did you know  
that you can now  
donate **quickly  
and securely online**  
using your credit card  
at*

**[www.msbaweb.org](http://www.msbaweb.org)?**

Simply go to the MSBA website  
and click on the  
“Make a contribution” link  
on the left side of the page.



# SBAA Conference Report

CONFERENCE / From Page 5

for newsletter design, fund-raising, programming and community outreach. Our own Massachusetts chapter took home first place for web-site design this year, thanks to our webmaster and designer, Peter Jablonski. Another very touching award was given to two soldiers from the Georgia National Guard for the rescue of "Baby Noor", a 2-month old Iraqi baby with spina bifida. Lacking the medical technology and equipment necessary for survival, Iraqi doctors sent Noor home to die. When American soldiers found her in her



**Two soldiers from the Georgia Army National Guard accept a Humanitarian award for the rescue of a two-month old infant with spina bifida, "Baby Noor", from an Iraqi village.**

home with her frightened family, they worked closely with both Iraqi and American officials to transport her to the United States where she received life-saving care from many dedicated specialists and healthcare providers. The story was quite moving and was described in detail by Dr. Roger Hudgins (Chief Neurosurgeon, Children's Healthcare of Atlanta) at a session on Wednesday morning.



**Yes, even Bugs Bunny and Daffy Duck were there!**

This year's conference had something for everyone. Some members find it more interesting to attend chat groups, learning from others that share the same condition. Others enjoy catching up on the latest surgery techniques and the newest catheters on the market. Whatever your preference, it's a stimulating experience and you will certainly learn something you didn't already know. It's never too early to start planning. Next year, we're off to Louisville, Kentucky! Hope to see you all there!

## MSBA Volunteer Opportunities

To find out more about new committees the MSBA is forming and how they fit into the larger picture of our organization as a whole, take a look at our Strategic Plan, now available on our web site ([www.msbaweb.org](http://www.msbaweb.org)).



From there you can use online forms to sign up as a volunteer for any of the following committees:

*Clinic Desk Volunteers* - contact Cara Packard  
*Canister Volunteers* - contact Ellen Dugan  
*Holiday Party Volunteers* - contact Jen Kuhar  
*Golf Tournament Volunteers* - contact Hyacinth Bellerose  
*MSBAYA Committee Volunteers* - contact Jen Kuhar  
*Picnic Volunteers* - contact Cara Packard  
*Potential new Board Members* - contact Brian Packard

## Items for Sale

Northeast Passage is selling a couple pieces of equipment. If you are interested in either, please give Dave a call or email at [david.lee@unh.edu](mailto:david.lee@unh.edu).

Quickie Mach 3 Upright handcycle. This handcycle is a 18 speed (3x6) bike with an additional low and high range and a coaster brake. It has an 18" seat and standard vertical handgrips, color is black. Seat and footrests are adjustable. Picture of a red Mach 3 can be seen at:

<http://www.nepassage.org/images/rpmach3.jpg>

It is in excellent condition, \$900 firm.

Natural Access Landeez Beach Chair. This chair needs some work but a couple hundred dollars into it will give some great access to very soft terrain. The chair is completely collapsible and features big balloon tires. Push handles are standard to push the user. Upholstery work and a possible tire may be needed to be useable. Picture of this chair can be seen at:

<http://www.nepassage.org/images/rpbeach.jpg>

\$250 firm.

# Contacts

**MSBA Telephone**  
MSBA Fax

**888-479-1900**  
978-649-8725

**SBAAB Telephone**

**800-621-3141**

## MSBA Officers

### **President**

**Brian Packard**

Email: bpackard@msbaweb.org

### **Vice President**

**Hyacinth Bellerose**

Email: hbellerose@msbaweb.org

### **Treasurer**

**Brendan Sullivan**

Email: bsullivan@msbaweb.org

### **Clerk**

**Jennifer Kuhar**

Email: jkuhar@msbaweb.org

## Board of Directors

**Matt Neal**

Email: mneal@msbaweb.org

**Ginny Briggs**

Email: gbriggs@msbaweb.org

**Peter Jablonski**

Email: pjablonski@msbaweb.org

## Operations

**Ellen Dugan**

Email: edugan@msbaweb.org

888-479-1900

## MSBA Regional Representatives

### **Southeastern Massachusetts**

Aimee & Brandon Shanks 508-587-6788

96 Pondview Circle

Brockton, MA 02301

Email: orchid03@yahoo.com

### **Central Massachusetts**

Jean Cusick 508-756-3918

28 Camp Street, Paxton, MA 01612

### **Cape Cod and the Islands**

Judy Morgan 508-896-5085

36 Scarborough Road, Brewster, MA 03631

Email: judjon1@comcast.net

### **Western Massachusetts**

Betty Niedzwiecki 413-774-3489

526 River Road, Deerfield, MA 01342

Email: bniedzwiecki@hotmail.com

### **North Shore / Merrimac Valley**

Cindy Ward 978-682-9330

25 Devon Court, North Andover, MA 01845

Email: muna000@aol.com

## Committee Chairpersons

### **Arnold Chiari Information**

Kevin & Maureen Walsh 781-337-2368

67 Spring Street, Weymouth, MA 02188

Also try World Arnold Chiari Malformation Association at

http://www.pressenter.com/~wacma/

### **Benefits Program**

Ellen Dugan

Email: edugan@msbaweb.org

### **Canister Collections**

Ellen Dugan

Email: edugan@msbaweb.org

### **Fundraising**

Hyacinth Bellerose

Email: hbellerose@msbaweb.org

### **Literature and Lending Library**

Danielle Everett 781-826-4485

21 Elm Street, Pembroke, MA 02359

### **Medical Issues**

Ginny Briggs

Email: gbriggs@msbaweb.org

### **Membership**

Matt Neal

Email: mneal@msbaweb.org

### **Memorial Donations**

733 Turnpike Street, #282

North, Andover MA 01845

978-683-6644

### **Parents Helping Parents**

Cara Packard

Email: cpackard@msbaweb.org

### **Public Awareness / Publicity - VOLUNTEER NEEDED**

### **Youth & Adults Group**

Jen Kuhar

Email: jkuhar@msbaweb.org

### **Wheelchair Sports**

Dick Crisafulli, Mass Hospital School

781-828-2440

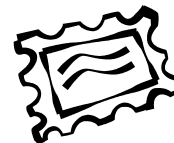
**Editor:** Peter Jablonski

**Asst. to the Editor:** Amy Blanchard

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



Massachusetts Spina Bifida Association  
733 Turnpike Street, #282  
North Andover, MA 01845  
Toll Free Phone: (888) 479-1900  
Web site: [www.msbaweb.org](http://www.msbaweb.org)



## Calendar of Events



Date	Event	Location
Sept. 13-15	Partner's for Youth with Disabilities MSBA Exhibit Booth	Hilton Hotel, Logan Airport
Sept 28	Hispanic Expo, MSBA Exhibit Booth	Children's Hospital, Boston
October	SPINA BIFIDA AWARENESS MONTH	
October 21	MSBAYA Lunch and Learn	Lexington Library, Lexington, MA
December 3	MSBA Holiday Party	Hampton Inn, Natick, MA
June 24-27, 2007	SBA National Conference	Louisville, KY

The MSBA Board of Directors meets the first Monday of every month at the Lahey Clinic in Burlington, MA. If the first Monday falls on a major holiday, the Board meets the second Monday of the month. Meetings begin at 7:00 PM. All members are welcome.



**Annual Board Meeting - October 2nd**  
**All Invited to Attend!**  
**Please RSVP Ellen Dugan (see Contacts on page 19)**