MSBA News

A Publication of the MASSACHUSETTS SPINA BIFIDA ASSOCIATION

MEMBER, SPINA BIFIDA ASSOCIATION OF AMERICA

- WINTER 2006 -



LETTER FROM THE PRESIDENT

By Brian Packard

Happy 2006! I hope that each of you had a beautiful holiday season filled with health and happiness. For the sports lovers among us, we are now hoping that with the Pats out of the playoffs, the Olympics will sustain us until pitchers and catchers report to Sox Spring training. For the non-sports nuts, we're just trying to count how many days are left to the first day of

spring. Hey, whatever keeps you going...



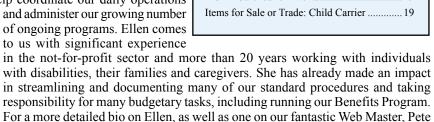
For the MSBA, it has been event after event, continued growth, streamlined operations and a continued sense of community. Our fall/winter season has already been highlighted by two wonderful events. Rosalie and Fiore Foti hosted a dinner and dance at the Danversport Yacht Club on Saturday, November 12, that was a huge smash. Through ticket sales and auctions, they

were able to raise money for the MSBA and Children's Hospital Boston. We are extremely grateful for the \$2,500 donation, which they presented to us at the Holiday Party just before our traditional Yankee Swap game. What a gift that was!

The rest of our holiday celebration was wonderful as well. The kids had a great time with arts and crafts, games and music (many thanks to Lauren Nordahl for coordinating!). As always, Santa was a huge hit with the kids, though I think I saw just as many smiles on the grown-ups as they watched the wrapping paper fly. Our thanks to the dozens of volunteers who helped coordinate the event, especially our MSBAYA members. And a special Ho! Ho! Ho! goes to tireless Board member Jen Kuhar, who helped coordinate the whole day.

You may have seen a new face at the party, hustling around to make sure the event went smoothly. That was our new Operations Associate, Ellen Dugan. Ellen joined us in October to help coordinate our daily operations

and administer our growing number of ongoing programs. Ellen comes to us with significant experience



Jablonski, see page 14. The MSBA Youth and Adults Groups has been

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CONTACT INFORMATION

MSBA TELEPHONE

888-479-1900

MSBA FAX 978-649-8725

MSBA OFFICERS

PRESIDENT

Brian Packard

Email: bpackard@msbaweb.org

VICE PRESIDENT Hyacinth Bellerose

Email: hbellerose@msbaweb.org

TREASURER Brendan Sullivan

Email: <u>bsullivan@msbaweb.org</u>

CLERK

Jennifer Kuhar

Email: jkuhar@msbaweb.org

BOARD OF DIRECTORS

Cori Couture

Email: ccouture@msbaweb.org

Matt Neal

Email: mneal@msbaweb.org

Ginny Briggs

Email: gbriggs@msbaweb.org

MSBA REGIONAL REPRESENTATIVES

SOUTHEASTERN MASSACHUSETTS

Aimee & Brandon Shanks
Brockton, MA 02301

Patricia DeMoranville
Email: pdcv1230@aol.com

Phone: 508-587-6788 Email: orchid502@yahoo.com

CENTRAL MASSACHUSETTS

Jean Cusick 508-756-3918

Paxton, MA 01612

CAPE COD & THE ISLANDS

Judy Morgan 508-896-5085

Brewster, MA 03631

Email: judjon1@comcast.net

WESTERN MASSACHUSETTS

Betty Niedzwiecki 413-774-3489

Deerfield, MA 01342

Email: <u>bniedzwiecki@hotmail.com</u>

NORTH SHORE / MERRIMAC VALLEY

Cindy Ward 978-682-9330

North Andover, MA 01845

Email: muna000@aol.com

SBAA TELEPHONE

800-621-3141

OPERATIONS ASSOCIATE

Ellen Dugan 888-479-1900

Email: edugan@msbaweb.org

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 888-479-1900

Email: edugan@msbaweb.org

CANISTER COLLECTIONS

Ellen Dugan 888-479-1900

Email: edugan@msbaweb.org

FUNDRAISING

Hyacinth Bellerose

Email: hbellerose@msbaweb.org

GOLF TOURNAMENT

Hyacinth Bellerose 978-649-8724

Email: hbellerose@msbaweb.org

LITERATURE & LENDING LIBRARY

Danielle Everett 781-826-4485

MEDICAL ISSUES

Ginny Briggs

Email: gbriggs@msbaweb.org

MEMBERSHIP

Matt Neal

Email: mneal@msbaweb.org

MEMORIAL DONATIONS

MSBA 888-479-1900

733 Turnpike Street, #282 North, Andover MA 01845

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

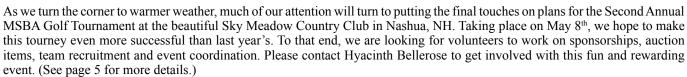
Dick Crisafulli, Mass Hospital School 781-828-2440

President's Letter - continued from page 1

busy this season as well, hosting a sports clinic at the Mass Hospital School in Canton in late September, a Game Day at Children's Hospital Boston in early November, and lunch at the Burlington Mall Uno's in January. Mark your calendars for the next big MSBAYA outing — an evening of jazz and much more, with vocalist, educator and recording artist Lisa Thorson. The MSBAYA has a limited number of tickets for this fully-accessible, multisensory performance on March 9th at the Wheelock Family Theatre in Boston. (See the MSBAYA Focus on page 8 for details.)

On Friday, April 14th, the Sullivan brothers will be holding their annual fundraiser at Boston Beer Works near North Station. This event has become an annual MSBA tradition and is always great fun. If you're interested in attending, see page 5 for details. In addition to the fundraiser, Brendan plans to cash in the

official number he earned in 2004, to run in the Boston Marathon, and once again, raise funds for the MSBA.





Finally, the MSBA is once again encouraging our members to attend the annual conference of the Spina Bifida Association of America, and providing financial assistance to help you get there. This year, the conference will be in Atlanta, GA from Sunday, June 25th through Wednesday, June 28th. Through our newly-updated MSBA Benefits program, you can *earn* up to \$1,750 toward conference expenses, by helping the MSBA. See pages 12 and 13 for Benefits Program details. Also, if you are thinking of attending conference, you might want to attend our Travel Readiness Seminar on Sunday, March 5th. See details on page 7.

Until golf and conference season arrives, I hope you stay warm, healthy and happy. — Brian Packard

FOTI FUNDRAISER RECAP

On Saturday, November 12, 2005, the Foti Family of Gloucester hosted a formal dinner dance at the Danversport Yacht Club. The event was very swanky and attended by some 200 of Rosalie and Fiore Foti's friends, relatives, and business associates. There was a DJ spinning tunes all night, a HUGE dance floor and delicious food for all in attendance.

Cori Couture of the MSBA Board of Directors presented a slide show of MSBA events



and gave a speech about what spina bifida is and isn't and how much we appreciated the support of all the guests. Board Member Jen Kuhar attended as well, with

5 of her friends. Also at the MSBA table were Beth Miller of Wenham and Ramona and Beverly Brewer of Essex.

Funds at the event were raised through tickets and a a raffle for a wide variety of gift baskets, prizes, and gift certificates. After the dust

settled, the Foti's, along with their daughter Bianca (who has spina bifida) and her cousin, attended the MSBA Holiday Party, where they presented our President Brian Packard with a check for \$2,500!

Rosalie and Fiore, we can't thank you enough for your generosity and incredible hard work!



'TWAS THE MSBA HOLIDAY PARTY

By Megan Gouveia

A snowy December 4th marked this year's holiday party. With approximately 90 people gathered at the Hampton Inn in Natick, it was a great kickoff to the holiday season!



The day began with a delicious spread of food and drink, while members gathered with old friends and welcomed new ones. Food was followed by a packed agenda for all. Arts and crafts, thanks

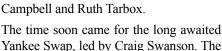


to Lauren Nordhal, was the first activity to capture the attention of the children. They were busy making bracelets, candle holders, and coloring their perfect picture for the coloring contest. Before long, everyone hurried to enter their guesses for the infamous mystery gift game and candy jar count.



As the day moved on, the children received

a special visit from Santa Claus himself. What better way to get into the holiday spirit than to welcome Santa by singing carols in front of a snowy window? We cannot forget to give a big thank you to Santa and his elves - Cara Packard, Sandy Campbell and Ruth Tarbox.





rules of a Yankee Swap can vary depending where it is played. In this instance, participants would choose a gift, open it and then decide whether or not they wanted to keep it or trade it for a gift already opened by an earlier participant. Although most decided to keep the gifts they picked, some hot items did see a few hands. This year's most desired gifts were bottles of wine (one of which came with chocolates) along with gift cards and games.



Now, an event like the Holiday Party cannot end without acknowledging all involved. Special thanks are in order for Jen Kuhar, who secured the hotel, organized, managed, and coordinated the planning for the day. Big thanks also to members of the Youth and Adults Group for all their hard work toward making this such a fun afternoon. Everyone is sure to be talking about it until our next outing. We look forward to seeing you all again at the Summer Picnic, if not before!

COLORING CONTEST WINNERS

CONGRATULATIONS to the following winners in our 2005 Holiday Coloring Contest. All of your entries were wonderful and added to the festive décor at our party!





Nathan Bellerose	Nikolaus Jablonski
Sophia Bellerose	Lana Knickerbocker
Abigail Bemis	Jodie Leach
Andrew Briggs-Neal	Katie Packard
Grace Briggs-Neal	Nico Parmeggiani
Andrew Callahan	Britney Poindexter
Shane Callahan	Erik Reidister
Maryhelen Fabiszewski	Anna Reidister
Bianca Foti	Katie Reilly
Julia Gouveia	Derek Scarlett
Katie Jablonski	Denzel Scarlett

JOIN US FOR THE SECOND ANNUAL

MSBA GOLF TOURNAMENT

Monday, May 8, 2006

AT THE SPECTACULAR



To GET INVOLVED

- As a Player As a Volunteer
- As a Sponsor To suggest a Sponsor,

Please Contact

Hyacinth Bellerose

Phone: 978-649-8724

Email: <u>hbellerose@msbaweb.org</u>



TICKET PRICES

- Golf, Lunch, & Dinner: \$150/person
- Dinner Only: \$35/person

* A special note: If you're applying for MSBA Conference Benefits: **Bringing your** pals to this Fundraiser can earn you credit toward our Extended Conference Benefits! (See page 13 for complete details.)

Full-Day Educational Conference



SPINA BIFIDA ASSOCIATION OF CONNECTICUT

Second Annual Conference for Education and Awareness

and

Kid'S Camp

A program for children with spina bifida and their siblings.

Saturday, March 25, 2006 8:15 - 9:00 AM Registration & Continental Breakfast

Conference: 9:00 AM - 4:00 PM

The Special Care Community Center New Britain, CT

You are invited to a full-day conference for education and awareness of spina bifida and its related issues. There will also be a Kid's Camp program for children with spina bifida and siblings while parents attend conference sessions.

Registration fee is \$10 per adult, \$5 per child with a maximum of \$25 per family. This fee includes a continental breakfast, lunch, and two snacks as part of the Kid's Camp.

For more information: call toll free: 1-800-574-6274 or Email: SBAC@sbac.org

FOURTH ANNUAL SULLIVAN BROTHERS

MARATHON FUNDRAISER

AT BOSTON BEER WORKS

Hosted by Brendan and Michael Sullivan



FRIDAY, APRIL 14, 2006
AT BOSTON BEER WORKS
CANAL STREET, BOSTON



Join Brendan and Michael Sullivan on Friday April 14th at Boston Beer Works on Canal Street (near North Station and the Fleet Center) in Boston. Come for free pool (with cue balls, not water) and appetizers. Then stay to outbid your friends in an auction for fantastic sports memorabilia and tickets.

Take this opportunity to visit with old friends, meet new ones, and, of course, to support the MSBA!

Admission is \$20 and gives you access to free appetizers and use of the pool tables all evening.*

* A special note: If you're applying for MSBA Conference Benefits: Bringing your pals to this Fundraiser can earn you credit toward our Extended Conference Benefits!

(See page 13 for complete details.)

SBAA ANNUAL CONFERENCE 2006:

SBAA'S 33RD ANNUAL CONFERENCE

June 25-28, 2006 in Atlanta, Georgia

THE OMNI HOTEL, CNN CENTER

100 CNN CENTER, ATLANTA, GEORGIA 30303
PHONE: (404) 659-0000, FAX: (404) 525-5050
http://www.omnihotels.com/FindAHotel/AtlantaCNNCenter.aspx

This year, the MSBA is making a special effort to assist members who need help with travel and travel arrangements. If you need assistance or would like more information, there are 2 things you should do:

- 1. Attend our **Travel Readiness Seminar** on March 5th (see facing page).
- 2. CALL OUR TOLL FREE NUMBER (888-479-1900) AND LEAVE US YOUR CONTACT INFO.

Conference 2006 — It's Time to Make Plans!

By Hyacinth Bellerose

The following is a partial listing of things to see and do in Atlanta. For the *full* listing, please visit our Web site at: www.msbaweb.org.

GENERAL INFO

• <u>www.atlanta.net</u> is the **official tourist information page for Atlanta**. However, I found <u>www.georgia.org</u> to be more useful. See also <u>www.helloatlanta.com</u>, <u>www.accessatlanta.com</u>, <u>www.atlantakids.net</u>, and http://www.atlantawalkabout.com (owned and run by Atlanta residents).

SPECIFIC ATTRACTIONS

- The Fernbanks Museum of Natural History offers permanent and special exhibits (including one all about chocolate, during the week of Conference!). The museum also has an IMAX theater, dinosaurs, a really cool shell exhibit, a field guide to the solar system, and much more. Visit www.fernbank.edu/museum.
- The Battle of Atlanta can be seen 15 times a day at the Atlanta Cyclorama. Presented in a three dimensional panorama with music and narration, the painting of the Battle of Atlanta forever captures a pivotal moment in the history of our nation. Visit www.bcatlanta.com.
- Into kangaroos? **The Kangaroo Conservation Center**, just outside Atlanta, boasts the largest collection of kangaroos outside of Australia.
- Visit CNN Studios (advance reservations for wheelchair access). More info at www.cnn.com/studiotour.
- Underground Atlanta is an historic site covering a five-block area, and includes features such as shopping, dining, an historic tour, nightlife, and re-occurring annual events. Underground Atlanta features more than 100 street vendors who provide face painting, magic tricks, toys, and fortune telling. See www.underground-atlanta.com.
- WORLD's LARGEST AOUARIUM JUST OPENED. For details, visit www.georgiaaquarium.org.
- Visit **World of Coca-Cola**, the Coca-Cola Museum. Details online at http://www.woccatlanta.com/.
- If you want to get out of the city, see www.stonemountainpark.org for activities ranging from a laser show to the summit skyride to "riding the ducks". It looks like a fun place to visit, but keep in mind that you'll need a car to get there.

GETTING READY FOR ATLANTA

SAVE THE DATE!!

FOR THE

MSBA TRAVEL READINESS SEMINAR



Sunday, March 5, 2006 from 12:30 - 4:00 pm at the Hampton Inn in Natick



If you are thinking of attending the SBAA Conference in Atlanta (June 2006) or are just interested in learning more about options for traveling with a disability, this is the event to attend!

WHAT WILL BE COVERED?

- How to prepare for a long trip, like attending the SBAA Conference in Atlanta.
- Your rights as an individual with a disability, and getting the most out of your journey.
- How to apply for MSBA Conference Benefits, as distinct from the regular MSBA Benefits Program of \$500 per year. (See pages 12 and 13 for more details.)
- How to help the MSBA run successful events, and, in return, receive credit toward extended MSBA Conference Benefits *up to* \$1,750.

Look for more information - coming to your mailbox soon. We hope to see you there!

NATIONAL KIDS CAMP SCHOLARSHIPS

SBA is pleased to announce the launch of National **Kids Camp Scholarships**. These scholarships are \$1,000 each and are for one parent/guardian and one child to attend the SBA National Conference. The \$1,000 scholarship will pay for conference registration for both (\$750) and can be used to subsidize transportation, lodging, or food costs while at the conference (\$250 subsidy). This campership is *only* for attendance at the National SBA Conference.

There are a minimum of 3 \$1,000 camperships available. Awardees will be selected by a national committee based on applicant need and parent statement. Each chapter will have the opportunity to forward 2 applications for review by the national review committee.

Application forms will be sent to the chapters in early February. Chapters will have until March 15, 2006 to accept applications and will then submit a maximum of 2 applicants to the National office by COB April 3, 2006. If you have any questions about this program or the campership selection process please contact Susan Schoenberg at 202-944-3285, ext. 11 or via e-mail at sschoenberg@sbaa.org.

SBAA COLLEGE SCHOLARSHIP APPLICATIONS

Completed applications are due to the SBAA postmarked no later than Wednesday, March 1, 2006.

Applications can be downloaded from the SBAA Web site:

- 1. Go to http://www.sbaa.org.
- 2. Click on *Programs*>Education.
- 3. Click on SBAA Scholarship Fund.

Alternatively, you can have the form emailed to you, or sent as a hard copy via postal mail.

Please contact Stephanie Boyer, SBAA Field Services Manager by email: sboyer@sbaa.org or 202-944-3285, ext. 21 for the application.

MSBA YOUTH & ADULTS GROUP

MSBAYA Focus

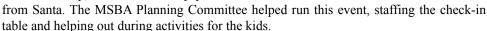


By Robyn Hand

The MSBA Youth and Adults Group has had a busy few months. On November 6th, about a dozen members came to Children's Hospital in Boston for a day of board games. There were some traditional games, like Scrabble, as well as a few not-so-traditional games, such as Red Sox Uno. A great time was had by all.



On December 4th, the entire MSBA organization came together for our annual Holiday Party. This year's event was held at the Hampton Inn in Natick. There were a lot of new faces, and those of us that have been in the group a while were pleased to see our group grow. The day was filled with fun, food, and music. The adults had a Yankee Swap, while the kids enjoyed a visit



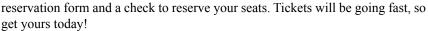
On January 22^{nd} , we met at Uno's at the Burlington Mall for lunch. The turnout was great and so was

the food and conversation. We all had a great time.

On March 9th, the Group will gather to attend a multimedia/multisensory Jazz Concert at the Wheelock College Family Theatre. Lisa Thorson started Lisa Thorson and



Company, a jazz quarter that has been performing together for over ten years. This performance sounds incredible and they have graciously offered the MSBAYA a limited number of tickets at \$10 a piece. You must send in a



The committee is working hard to plan events for the rest of the year. Watch your mail, the Yahoo! Group, and the Web site for information on upcoming events.



UPCOMING MSBAYA EVENTS

Once again, your MSBAYA Planning Committee has been busy coming up with new events and activities for gathering and socializing. Watch your mailboxes, the MSBAYA Yahoo! Group and the MSBA Web site (www.msbaweb.org) for more information. Don't miss out on all the fun! Below is an abbreviated list of upcoming Youth and Adults Group activities. For full listings, please see the Calendar on page 19.

•	March 5, 2006	Travel Readiness Seminar (12:30 pm - 4:00 pm), Hampton Inn, Natick, MA. (See page 7)	
	If you're thinking	f attending the National Conference this year, we strongly recommend that you attend this event!	!

•	March 9, 2006	MSBAYA Lisa Thorson Jazz Concert (7:30 pm), Wheelock Family Theatre, Boston, MA
•	April 14, 2006	Sullivan Brothers Fundraiser (8:00 pm), Boston Beer Works, Boston, MA

•	April 22, 2006	MSBAYA Board Game Day (12:30 - 4:00 pm), Children's Hospital, Boston, MA

May 1, 2006 MSBA Conference Benefits Application Deadline, send Application to MSBA

• May 31, 2006 **Jean Driscoll Scholarship Application Deadline**, send Application to MSBA

June 3, 2006 Combined MSBAYA & MSBA Parents Event, Location and details, TBD

• June 25-28, 2006 SBAA Annual Conference, Atlanta, GA

MSBA YOUTH & ADULTS GROUP COMMITTEE

Robyn Hand

Phone: 781-665-5116 Email: rlhand97@aol.com

Jen Kuhar

Phone: 508-620-3963 Email: jenkuhar@msn.com

Lindsay Meuse

Phone: 781-254-4925 Email: <u>lmeuse124@aol.com</u>

Aimee & Brandon Shanks

Phone: 508-587-6788 Email: orchid502@yahoo.com



JEAN DRISCOLL SCHOLARSHIP APPLICATION DEADLINE: May 31, 2006

The MSBA Board of Directors is now accepting nominations and applications for the 4th Annual Jean Driscoll Scholarship.

The MSBA offers this program as a tribute to eight-time Boston Marathon Champion and adult with spina bifida, Jean Driscoll. The scholarship will be awarded to an MSBA member with spina bifida who best demonstrates the character and determination of the scholarship's namesake. This \$1,000 award may be used for educational, developmental, or assistive programs or needs.

To be considered, or to nominate someone, please send a one-page letter, describing why the individual should be considered for this award to:

B

MASSACHUSETTS SPINA BIFIDA ASSOCIATION
733 TURNPIKE STREET, #282
NORTH ANDOVER, MA 01845



New Members Needed for THE MSBAYA PLANNING COMMITTEE



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 at the top of this page.

ADULT HEALTH CARE GUIDES!

THE SBAA HAS PROVIDED THE MSBA WITH HEALTH CARE GUIDES FOR ADULTS WHO HAVE SPINA BIFIDA.

WE HAVE COPIES AVAILABLE ON CD-ROM OR PRINTED, IN 3-RING BINDERS.

IF YOU WOULD LIKE ONE, PLEASE LEAVE A MESSAGE ON THE MSBA'S VOICE MAIL SYSTEM

(888-479-1900).



MSBA Membership Information

The 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.

- A few of the benefits members enjoy include meetings, a strong Youth and Adults Group, fundraising, an extensive Benefits Program, social events, a developing Parents Helping Parents program, a Parents' Chat Group, online discussion groups, and a lending library.
- 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 for ongoing events and programs.
- "Qualified Applicants" to the Association receive the MSBA's quarterly newsletter, the SBAA's newsletter *Insights*, and may receive other MSBA benefits.
- There is no membership fee, but tax deductible donations are appreciated. *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.

- Who is a "Qualified Applicant"? A person with Spina Bifida who resides in Massachusetts or a New England state that does not have its own SBAA affiliated entity. Benefits are available to only one person per family, unless there is more than one person with Spina Bifida within that family.
- 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 <u>mneal@msbaweb.org</u>.

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 from 7:00 to 9:00 PM. 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 our Operations Associate, Ellen Dugan (see inside front cover).

 The MSBA held its bi-annual officer elections at our Annual Meeting in November. The results were unanimous and each Officer will hold a two year term:

> Brian Packard – President Hyacinth Bellerose – Vice President Brendan Sullivan – Treasurer Jen Kuhar – Clerk

- MaryJo Dunleavy of Boston Children's Hospital attended the MSBA's Annual Meeting and asked that the MSBAYA Group try to host activities to integrate parents and children with spina bifida.
- To assist Boston Children's Hospital with assessing how best to meet the needs of individuals with spina bifida, the MSBA has offered to participate in a User's Group.
- Planning for the 2006 Golf Tournament (Monday, May 8) is well underway. The Golf Tournament Committee had its first meeting in January.
- The MSBA would like to distribute information packets to new

- and expecting parents. Ellen Dugan is putting ideas together.
- The Annual Picnic will tentatively be held the third weekend in July. Specific date and location to be confirmed soon.
- After a very successful 2005 Holiday Party, the MSBA has already booked the Hampton Inn in Natick again for next year's party. The date will be Sunday, December 3, 2006.
- The MSBA will be holding a travel readiness seminar on March 5th at the Hampton Inn, Natick (see page 7). This event will be geared to those planning to attend the SBAA's Annual Conference in Atlanta, GA from June 25-28, 2006.
- Ellen is investigating opportunities for outside entities to fund postage for the MSBA's newsletter distribution. She is also looking into grant options, and putting together a list of resources for a future MSBA Resource Guide.
- A lengthy discussion was held about how to promote participation of members residing in Western Massachusetts.
 The MSBA will investigate hosting an event in Western Massachusetts in the future.



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) Please check one: Family (Parent(s) of Child with spina bifida) **NEW Membership** ____ Associate (Interested Friend or Family Member) Renewal Medical Professional 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...): Please tear out this application form and return it to: **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. SEE BELOW FOR DETAILS.

WHO QUALIFIES FOR BENEFITS?

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

ANNUAL BENEFITS PROGRAM

A qualified applicant is entitled to \$500 per year to enhance independence, increase mobility or otherwise improve his/her life as it is affected by Spina Bifida. These funds may be used for braces, crutches, canes, catheters and continence supplies, summer camp, assistive technology, educational items, or other similar expenses.

All benefits applications must be submitted in writing to the MSBA Operations Associate, via postal mail or email. The application will be reviewed for approval at the following month's Board of Director's meeting. The application will be approved *only* if the applicant provides proper documentation and proof of eligible expenses. This may be done in two ways:

- 1. <u>Reimbursement</u>: The Qualified Member must present receipts showing payment for eligible expenses already incurred. Once these receipts are received and reviewed, the MSBA will write a check to be paid to the applicant, parent or guardian as reimbursement.
- 2. <u>Direct Pay</u>: 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.

BENEFITS APPLICATIONS RECEIVED WITHOUT PROPER DOCUMENTATION WILL BE RETURNED WITH A NOTE EXPLAINING WHAT IS MISSING. PROPER DOCUMENTATION MEANS: 1) A BENEFITS FORM, PROPERLY FILLED OUT AND 2) RECEIPTS FOR EVERY ITEM TO BE COVERED BY THE MSBA OR THE BILL OR INVOICE TO BE DIRECT PAID. So... Save yourself some time, and make sure you have included all the necessary paperwork and receipts the first time out!

2006 SPECIAL CONFERENCE PROVISIONS

EARN UP TO \$1,750 TOWARD CONFERENCE EXPENSES!

The MSBA Board of Directors has created a new program for earning and applying for Conference benefits. Qualified Applicants can receive up to \$750 toward attending the SBAA Annual Conference, just by filling out an application. To *earn* extended Conference Benefits, which bring the possible total up to \$1,750, Qualified Applicants must provide a service or services to the MSBA, by taking actions listed on the form on the facing page.

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.

MSBA BENEFITS FORM Name: Street Address: City, State, Zip: ___ Telephone: Email: MSBA REGULAR Annual Benefit (Level 1) \$500 \$500 Get \$500 Annual Benefit just by applying and providing proper documentation.* Yours **PLUS** FOR **CONFERENCE BENEFITS** FREE! 2006 Conference Benefit (Level 2) Add \$250 to your total (for Conference Expenses) just by \$250 applying (with proper documentation). EXTENDED CONFERENCE BENEFITS **PLUS** *** EITHER *** 2006 Conference Benefit (Level 3a) add \$500 Add \$500 to Levels 1 & 2. Help the MSBA by doing any one of the following: • Get 2 Golfers to sign up for the MSBA Golf Tournament • Bring 5 paid attendees to the Boston Beer Works Fundraiser. • Place and monitor 5 collection canisters in local businesses. Work FOR YOUR BENEFITS \$1,000 2006 Conference Benefit (Level 3b) add \$1,000 Add \$1,000 to Levels 1 & 2. Help the MSBA by doing any one of the following: • Get 4 Golfers to sign up for the MSBA Golf Tournament GRAND • Bring 10 paid attendees to the Boston Beer Works Fundraiser. TOTAL • Place and monitor 10 collection canisters in local businesses. REQUESTED **QUALIFIED EXPENSES: DETAILS** Conference expenses that can be reimbursed are: airfare, up to 5 nights hotel accommodations at SBAA rate, reasonable food costs (excluding alcoholic beverages), transportation to and from airport, Conference Registration, and Awards Luncheon. Please note: No funds will be distributed in advance of the Conference other than those paid directly to vendors or the SBAA. All expenses submitted for reimbursement must be accompanied by a receipt. APPLICATION DEADLINE: MAY 1, 2006 * Below, please include an explanation of the benefit you are requesting and what Please tear out this application it will be used for. Attach extra pages, if necessary. See previous page for details on form and return it to: proper documentation. Ellen Dugan **MSBA Operations Associate** 733 Turnpike Street #282 North Andover, MA 01845

Who's Out There?

(MSBA MEMBER SPOTLIGHT)

THIS MONTH'S FEATURED MEMBERS:

OUR NEW! AND FABULOUS OPERATIONS ASSOCIATE AND OUR WONDERFUL WEB MASTER



ELLEN DUGAN, NORTON, MA (Operations Associate)

The newest member of the MSBA team lives with her husband, Tom, their 2 children Michael (age 12) and Emily (age 7), and their very hyper Golden Retriever, Chrissy, in Norton, MA. Ellen comes to the MSBA with many years of experience in the not-for-profit sector, as well as more than 20 years working with individuals with disabilities, their families, and caregivers. Ellen received her Bachelor's Degree in Education from Bridgewater State College and her Master's in Social Work from Boston College. She looks forward to working with the MSBA Board of Directors and membership to meet the goals of the Strategic Plan and to help the organization

continue to grow. Ellen spends her spare time shuttling her children around town, reading, traveling (preferably to warm climates), and during the summer, as much time as possible at the beach.



PETE JABLONSKI, DUNSTABLE, MA (Web Master)

Pete lives with his wife, Lynn, their two children Nik (age 11) and Katie (age 8), Buddy the Golden Retriever, Dillan the Chocolate Lab/Shepard, Sinny and Wooly (guinea pigs), and a few other animals in Dunstable. Pete is responsible for designing and maintaining the current MSBA Web site. He got involved with the MSBA after being contacted by Hyacinth Bellerose who had seen some of his other Web site work. He works as a bioinformatics scientist for the Swiss company, Genedata AG, which develops enterprise-level software for large pharma and biotech companies, doing drug discovery.

In his spare time Pete enjoys woodworking, canoeing, camping with the Cub Scouts, and while he's a big Sox fan his heart will always be with the Chicago Cubs (much to the delight of his kids).

Working with the MSBA has been a pleasure, in part because it's a well-run non-profit organization with defined goals, but also because the members are really great people who accomplish amazing things despite physical limitations. Pete looks forward to a continued relationship with the MSBA.

A SPECIAL DONATION FROM AN ORGANIZATION WITH A BIG NAME

Chances are that most of you have never heard of the Eastern Collegiate Athletic Conference - Sports Information Directors Association or ECAC-SIDA. (Quite a mouthful, isn't it?) Well, apparently, they had heard of us. According to MSBA Treasurer Brendan Sullivan, who works with one of ECAC-SIDA's members, this professional organization chose to sponsor the MSBA as part of their annual giving program last year. As a result, they presented the MSBA with a check for \$1,500! You've heard of them now, so if you happen to meet any members of ECAC-SIDA in your travels, be sure to tell them thanks!!

KIDS! DO YOU HAVE AN EXPERIENCE YOU'D LIKE TO SHARE?



WE'D LOVE TO HEAR FROM YOU.

WRITE A STORY OR POEM DRAW A PICTURE

TAKE A PHOTO



Then, send it along to us via postal mail or email (see back cover) and we'll run it in the MSBA News!

MSBA VOLUNTEER OPPORTUNITIES

To find out more about committees the MSBA is forming and how they fit into the larger picture of our organization as a whole, have a look at our Strategic Plan on our Web site: www.msbaweb.org.

From there, you can also use online forms to sign up for any of the committees listed. You can also contact our Operations Associate, Ellen Dugan, at the MSBA's Toll Free number: 888-479-1900 or via email: edugan@msbaweb.org.

COMMITTEES AND VOLUNTEER OPPORTUNITIES:

- · Clinic Desk Volunteers
- · Canister Volunteers
- Golf Tournament Volunteers
- MSBAYA Committee Volunteers
- Picnic Volunteers
- Potential new Board Members

ADVOCACY ALERT!

YOUR ADVOCACY EFFORTS HAVE PAID OFF!

Congress has provided the National Spina Bifida Program (NSBP) with a total of \$5.049 million for the coming year. That's a \$1.392 million increase over last year's allocation!

This means that the programs that we have put in place will continue to thrive and we will be able to continue with much-needed research, quality-of-life initiatives, and folic acid education and awareness efforts.

Please take the time to send a THANK YOU note to your Congressional Representatives for supporting people like us, who are living with spina bifida every day.

To send an email, simply go to http://www.sbaa.org and click on the red, white, and blue icon that says ACTION ALERT in the right hand column, "What's New at SBA?"

APPLICATIONS ARE NOW BEING ACCEPTED FOR THE MSBA BOARD OF DIRECTORS

The MSBA Board of Directors is looking to expand its ranks. We need new Board members, especially people with *expertise in the following areas*:

Finance
Public Relations
Fundraising
Medical Fields / Health Care
Social Work

PLEASE SEND INQUIRIES TO:

Prospective New Board Members Massachusetts Spina Bifida Association

733 Turnpike Street, #282 North Andover, MA 01845

THE PLAYGROUND PROJECT AT MASON-RICE ELEMENTARY SCHOOL

149 PLEASANT STREET, Newton Centre, MA

BY JOANNE MEAD

Three years ago, the old fire engine, which sat in a sand lot off the main playground, was slated to be replaced. The PTO ran a piece in the school notes, informing parents of the City's safety concerns with the rusty old engine and their request that it be removed. (The City of Newton's Parks and Recreation Department is responsible



for maintaining play grounds at the fifteen elementary schools.) My daughter Marianne had just entered kindergarten in the school, and although she longed to make friends, there was almost nothing she could do on the playground except blow bubbles with

her aide and hope that one of her peers would stop by to play with her. I called Katy, then the PTO co-president, after reading of the PTO's plan for the playground, and posed my thought: why not use this as an opportunity to create an accessible space in the play area?

Little did we know how hard and how long we would work to make what seemed so simple, so logical, so right, a reality.

We were surprised at how difficult it can be to create a truly accessible play space on a limited budget and with limited space. As we contemplated the scope of the playground project and started to despair at our budget constraints, hope stepped in. Our then-babysitter and BC student, Janelle Tribble, offered to run the Boston Marathon and the Massachusetts Spina Bifida Association agreed to back her and donate a portion of what she raised to the playground project. Janelle netted over \$15,000 in donations, and Mason-Rice received almost \$10,000 of that. We were off and running.

Why is it important to have play areas in schools (and



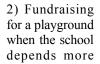
communities) accessible to people with mobility challenges?

- 1) When children with special needs and typically-developing children work and play together, they learn from each other. When children with special needs are given the opportunity to be included, they learn independence, they build confidence and self esteem, and they feel respected. Their peers learn too: inclusion facilitates caring relationships, aids in the development of empathy and connectedness, and fosters mutual respect.
- 2) Our school playground is also used by the community, as it abuts a baseball field and a larger city playground. Caregivers who have mobility impairments can interact with children when the play space is accessible. For example, two of the parents of students at Mason-Rice use wheelchairs and before this space was renovated, they had to situate themselves away from their playing children on the concrete path.

HURDLES FACED?

1) Cost of installation of rubber matting as a surface is expensive, and yet it is the only safe surface near play equipment that children with mobility issues can move freely upon. Bark mulch

and sand inhibit children with mobility issues from interacting with their peers on a playground. We paid almost as much for the rubber surfacing as we did for the play equipment.





and more on PTO fundraisers for basics like technology or teacher supplies is difficult. More than half of the money for the project was raised privately, and the PTO paid for the remainder. The City of Newton is responsible for replacing and maintaining playgrounds, but there are 15 elementary schools, and there is a list. Our school was number 12 on the list, I think, and would not have been eligible for any City funding for years.

3) Finding truly accessible play structures or equipment was much harder than it seemed it should be. Ramps make play structures accessible, but they take up a lot of space and need to be surrounded by lots of equipment, which is then expensive. There are very few stand-alone pieces of equipment on the market which are accessible. We put in swings (one of which has a specially-designed seat for a child with special needs); we did put in a fire engine (not accessible but we added two play panels to it that a child in a wheelchair can access), and a picnic



table that is accessible on both ends and that has a roof over it to provide shade.

4) There are logistics to putting in a play ground that make the project time-consuming, but which are not obvious to the eye. We needed to have an engineering plan and to design a retaining wall for dirt that was moved around the 4,000 square foot space. We needed to install cache basins and water drainage wells. We needed to pass the Conservation Commission's guidelines concerning water drainage and a nearby brook. We had to present to a Parks and Recreation Commission to get final approval on our design plan. There were countless meetings about equipment choice and placement, and we had numerous meetings with the City to ensure that safety standards were met.

Editor's Note: As you can see, the Mason Rice School Playground was built, and was opened and christened this past fall. When it was all finished, Joanne Mead sent this thank you note, along with pictures of the playground in all its glory.

Dear Brian,

Please extend our sincere thanks to the Board at MSBA for contributing so generously to the universal playspace at Mason Rice. The playground addition has made a big difference in Marianne's ability to interact with her peers... and we now have a second child at the school in a wheelchair.

I've enclosed pictures of the space that MSBA made possible. I remain available to answer any questions or to brainstorm with anyone you know of who hopes to create a similar play area.

With sincere thanks,

JoanneMead, for the Mason Rice PTO



DONATIONS & SPECIAL CONTRIBUTIONS

In Memory of Dr. Gilbert Bellerose:

- Ms. Mildred Coyne of Westborough, MA
- Sherrill & Marylou Cenna of Westborough, MA
- Ernest B. Sheldon, Sheldon Law Offices, P.C. of Pepperel, MA
- Mr. & Mrs. George Guertin of Holden, MA
- Dr. James & Mrs. Karen Esper of Worcester, MA
- Mr. & Mrs. Ted Jasiewicz of Westborough, MA
- The Rohald Family of Westborough, MA
- The Tierney Family of Westborough, MA
- Mr. & Mrs. A.J. Saitas of Taunton, MA
- Mrs. Marlene Hallice of Shrewsbury, MA
- Mr. & Mrs. Thomas Imse of Westborough, MA
- Mr. & Mrs. Donald Thatcher of Westborough, MA
- Mr. & Mrs. John Pescosolido of Berlin, CT
- Gerald & Katherine Marosek of Fairfax, VA
- William & Helen Webber Jr. of Westborough, MA

In memory of *J. Raymond Landry*:

- Cameron Larson of West Newton, MA
- Ruth Anderson & Family of Waltham, MA
- Mr. & Mrs. Joseph Steele of Portsmouth, RI
- Mr. & Mrs. Paul Coyle of Eldridge, IA
- Mr. & Mrs. Raymond Estlick of East Bridgewater,
 MA
- Dana & Susan Safford of Burlington, MA

Special thanks to Mr. Henry Walsh for his generous donation in memory of *Mary Helen Walsh*.

MSBA Member Donations, Fall 2005 / Winter 2006

- Nancy & Casey Hinckley of Cambridge, MA
- Dawn Mills of Brockton, MA
- John & Linda Fox of Madison, CT
- Lawrence & Lillian Chenier of Ludlow, MA
- Ryan Brown of Hanson, MA
- Ruth Silva of New Bedford, MA
- Christine & Virginia Wynne of Springfield, MA

BITS AND PIECES

...from Web sites to single events to quick tips...

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

By Hyacinth Bellerose

- AN INTERESTING READ Check out the book *Out of the Bottle*. It is an inspiring and fascinating account of determination and achievement in adversity. Graham Webb, a high school dropout at age fifteen, grew up in London, in government subsidized housing, and overcame the challenges of congenital spina bifida to forge a name in the world of business and haircare. Graham Webb has been knighted by Her Majesty the Queen for "Services to Business, and Charity in Kent." See http://www.out-of-the-bottle.com.
- OBTAIN OR DONATE DRESS CLOTHES Whether you have suits to donate or need clothes for a new job, take a look at the Web site www.dressforsuccess.org. The mission of Dress for Success is to advance low-income women's economic and social development and to encourage self-sufficiency through career development and employment retention. Dress for Success responds to the needs of our communities by providing programs that help economically disadvantaged women acquire jobs, retain their new positions, and succeed in the mainstream workplace. Dress for Success is a not-for-profit organization that offers services to help our clients enter the workforce and stay employed. Each Dress for Success client receives one suit when she has a job interview and a week's worth of separates when she gets the job.
- CLOTHES TO FIT PHYSICAL CHALLENGES Nathan had a G-tube when he was a baby and it was hard to find clothes that were comfortable, would hold the tube secure, and still provided easy access. If you have a clothing wish (a jacket that closes in the back but looks "normal", swim pants, etc.), you may find it at www.special-clothes.com. This is a local company out of Harwich, MA. You can also order a catalog by calling 508-385-9171. They even note whether latex is found in any of the clothing. Let me know if you try out any of the products.
- RESEARCH STUDY ON WEIGHT AND EATING HABITS Penn State is conducting a research study on the relationship between eating habits, obesity, and bowel habits among children with spina bifida. Children with spina bifida aged 3 to 18 years and their parents are eligible to participate. The study involves having parents or caregivers complete a questionnaire that will take no more than 15 minutes. The researchers are not gathering any identifying information such as names or addresses. All participation is completely voluntary. This research is being conducted by Keith Williams, Ph.D., Feeding Program, Penn State Hershey Medical Center and Kimberly Schreck, Ph.D., Psychology Program, Penn State Harrisburg. You can contact them by email at: feedingprogram@hmc.psu.edu or by telephone: 717-531-7117. This is an SBA approved study.
- Buy Books to Benefit the MSBA A Leominster bookstore has a program where a portion of the profits from each purchase results in a donation to the MSBA. Order at www.smileysbookstore.com and use the code "MSBA". They have books, gift items, small toys, etc. Every little bit adds up!
- A DIFFERENT KIND OF MUSEUM At the MIT Museum, you can: 1) See robots that once roamed MIT's Artificial Intelligence Lab. 2) Learn why a perfectly brilliant engineer would shoot an apple with a .45 caliber rifle.

 3) See computers with less memory than a pocket calculator but as big as a washing machine. 4) Make a wishbone walk. 5) And much, much more. This is a relatively small museum, so it's not overwhelming and the exhibits are amazing. Check out http://web.mit.edu/museum/visiting/index.html. Address: MIT Museum, 265 Massachusetts Avenue, MIT Bldg N52, Cambridge, MA. Phone: 617-253-4444. Admission is free the third Sunday of each month!!!
- WE NEED HELP WITH THE GOLF TOURNAMENT! Yes, I must finish up with a request. We need volunteers. We need sponsors. Does your company offer sponsorships? Do you have any great ideas of companies to approach?. We need auction items and golfers to participate in the event. See the box on page 5 for more information about the tournament.
 - Also, keep in mind that volunteering and helping us find sponsors and players can help you to earn funds toward attending the SBAA Annual Conference in June. Check out our new Conference Benefits Program on pages 12 and 13 for details. It is definitely worth your while to help out!!

Disclaimer: The resources, events, requests for participation in studies, entertainment options, and other information provided in this newsletter are provided solely for informational purposes. The MSBA does not endorse any of this information or these resources unless it is specifically funded by the MSBA. You are encouraged to review all information available by the sponsor of the resource or activity prior to providing any information about yourself or attending an event.

MSBA CALENDAR OF EVENTS

DATE EVENT LOCATION

Regarding Board Meetings: The Board meets on the first Monday of every month at the Lahey Clinic in Burlington. If the first Monday falls on a major holiday, the Board meets the second Monday of the month.

• N	March 5, 2006	Travel Readiness Seminar (12:30 pm - 4:00 pm)	Hampton Inn, Natick, MA
• N	March 9, 2006	MSBAYA Jazz Concert (7:30 pm) Lisa Thorson Multimedia Performance	Wheelock Family Theatre, Boston, MA
• N	March 20, 2006	MSBAYA Planning Committee Meeting	McDonald's, Norwood, MA
• A	April 14, 2006	Sullivan Brothers Fundraiser (8:00 pm)	Boston Beer Works, Canal Street, Boston, MA
• A	April 22, 2006	MSBAYA Board Game Day (12:30 - 4:00 pm)	Pavilion Conference Dining Rm, Children's Hospital, Boston
• N	May 1, 2006	Conference Benefits Application Deadline	See page 13
• N	May 8, 2006	MSBA Golf Tournament	Sky Meadow Country Club Nashua, NH
• N	May 15, 2006	MSBAYA Planning Committee Meeting	Location, TBD
• N	May 31, 2006	Jean Driscoll Scholarship Application Deadline	See page 9
• J _l	une 3, 2006	Combined MSBAYA & MSBA Parents Event	Location and details, TBD
• Ju	une 25-28, 2006	SBAA Annual Conference, Atlanta, GA	Omni Hotel, CNN Center, Atlanta, GA
• D	December 3, 2006	MSBA Holiday Party (12:30 - 5:00 pm)	Hampton Inn, Natick, MA

For the most up-to-date info on MSBA events and info, visit our Web site (www.msbaweb.org) and sign up for our online discussion groups: msbaya@yahoogroups.com and <a href="mailto:msbaya@yahoogroup

ITEMS FOR SALE, DONATION, OR TRADE

If you have equipment, toys and gadgets related to spina bifida that you're looking to sell, trade, or give away, here's your chance. If you have an item that you'd like to list, please describe the item, whether you want to sell, trade or give it away, and send it to the MSBA address on the back of this page.

A member of the MSBAParents Yahoo!Group has a **CHILD CARRIER FOR DONATION**

DETAILS: Sherpani Packs "Rumba" - Backcountry Child Carrier, for walking, hiking, camping, etc. Backpacking suspension for comfort and control; holds child upright comfortably and securely with padded foam and five security straps.

- Adjustable suspension
- Removable kid's daypack
- Elastic toy loop
- Foot stirrups for child's leg circulation
- Fully padded bucket seat & sides
- Rated to carry 70 pounds
- Sunshade
- Weight: 7 pounds 8 ounces

PRICE: FREE! Either pick up or pay the cost of shipping.

INTERESTED? CONTACT: Gary at greidister@nscap.org.



MASSACHUSETTS SPINA BIFIDA ASSOCIATION

733 Turnpike Street, #282 North Andover, MA 01845

Phone: 888-479-1900

Web site: www.msbaweb.org



PLEASE SUBMIT ARTICLES AND INFORMATION FOR PUBLICATION TO:

CORI COUTURE

C/O MSBA

733 TURNPIKE STREET #282

NORTH ANDOVER, MA 01845

Email: coricouture@msbaweb.org

UPDATE YOUR MEMBERSHIP TODAY!

MEMBER FEE IS **OPTIONAL** TO INDIVIDUALS WITH OR FAMILIES OF INDIVIDUALS WITH SPINA BIFIDA.

(SEE PAGES 10-11 FOR DETAILS)

Newsletter Editor: Cori Couture

You can view this and previous newsletter issues in full color on our web site: www.msbaweb.org

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.