MSBA NEWS

A PUBLICATION OF THE
MASSACHUSETTS SPINA BIFIDA ASSOCIATION

MEMBER, SPINA BIFIDA ASSOCIATION OF AMERICA

- SPRING 2006 -


Waiting for the shotgun start!


It was great to see so many women playing this year. You go, girls!

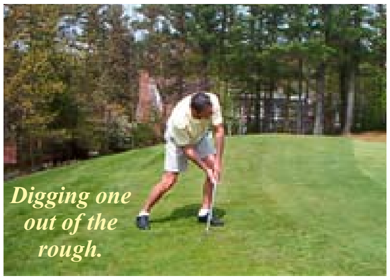

Ready to hit the links!


Nice swing!

The Second Annual MSBA Golf Tournament!

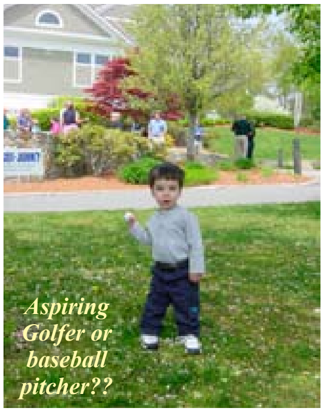

We're Number 1!


Posing by the "Longest Drive" marker.


Digging one out of the rough.


Ready?
Aim
Sink it!


11th Hole Hangout - waiting for a hole-in-one.


Aspiring Golfer or baseball pitcher??


Team Nathan & Eddie Ready for action!

CONTACT INFORMATION

MSBA TELEPHONE 888-479-1900
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MSBA OFFICERS

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

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Email: edugan@msbaweb.org

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GOLF TOURNAMENT
Hyacinth Bellerose 978-649-8724
Email: hbellerose@msbaweb.org

LITERATURE & LENDING LIBRARY
Danielle Everett 781-826-4485

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MEMBERSHIP
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North, Andover MA 01845

PARENTS HELPING PARENTS
Cara Packard
Email: cpackard@msbaweb.org

PUBLIC AWARENESS / PUBLICITY - VOLUNTEER NEEDED

YOUTH & ADULTS GROUP
Jen Kuhar
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WHEELCHAIR SPORTS
Dick Crisafulli, Mass Hospital School 781-828-2440

LETTER FROM THE PRESIDENT

BY BRIAN PACKARD


Brian with his parents at the Golf Tournament

Spring 2006 is a busy time for the MSBA. The golf tournament, SBAA conference planning, Boston Marathon, and other activities have kept the Board and many volunteers running at a fever pitch.

One person well-accustomed to this pace is Cori Couture. For almost 6 years, Cori has provided tireless leadership of many MSBA activities as a member of the Board of Directors, including serving as *MSBA News* editor. Cori has decided to leave the MSBA Board and editor posts to focus on work, family, and other projects. On behalf of the entire Board, I would like to thank Cori for her exceptional service and warm friendship.

As we head into summer, please take some time to ensure your final preparations are being made for this year's Annual Conference of the Spina Bifida Association of America. We hope to see many of you in Atlanta, GA from Sunday, June 25th through Wednesday, June 28th. Please don't hesitate to contact Ellen Dugan at 888-479-1900 with any questions related to conference. Remember, we are here to help.

Many thanks to Brendan and Michael Sullivan and Amy Fleming for all of their hard work, preparation and sacrifice in completing this year's Boston Marathon on behalf of the MSBA. Together, they were able to raise $6,500 for our cause. Thanks also to all those who attended their pre-race events and those that came to cheer them along the marathon course.

On the topic of running, I am happy to announce that Team MSBA is back! In April, we were notified by the directors of the Falmouth Road Race that Team MSBA would be granted 15 charity entries for the August 13th race. This is the 34th running of the world-renowned race, and we are honored to become a part of its tradition of helping local not-for-profits to raise funds. If you know of someone who would like to be a part of Team MSBA or coordinate the fundraising effort, please let us know.

Finally, thank you to everyone who helped make the Second Annual MSBA Golf Tournament at Sky Meadow Country Club in Nashua, NH a great success. Thanks to the efforts of Hyacinth Bellerose and many others, the tournament hosted over 90 golfers and raised thousands of dollars for the MSBA. This is sure to become yet another wonderful annual tradition for our growing and thriving organization.

Enjoy a healthy and happy spring. See you in Atlanta!

— Brian Packard


The EAA World War II Warbirds Squadron did a "fly-over," above the Sky Meadow Country Club, just before the shotgun start of the Golf Tournament.

INSIDE THIS ISSUE

TEAM MSBA: BOSTON MARATHON 2006

Although the MSBA was not part of the official Charity program at the Boston Marathon this year, we did have three people running the race and raising money for us. Long time Team MSBA Members Brendan and Michael Sullivan held their annual fundraiser on Friday, then ran in the Marathon on Monday. Meanwhile, a new member of our team, Amy Fleming offered to run on our behalf, and we gratefully accepted! All told, Brendan, Michael, and Amy raised $6,500. Not bad for an unofficial team, huh? See below for details.

THE SULLIVAN BROTHERS ANNUAL BOSTON BEER WORKS FUNDRAISER

BY MICHAEL SULLIVAN


Brendan and Michael on the race route, in their rockin' Team MSBA singlets!

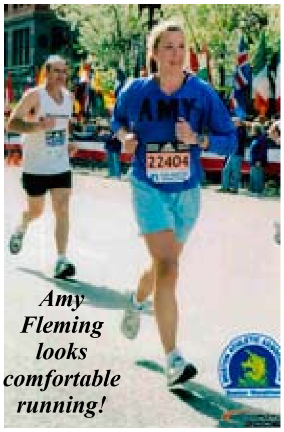
The Annual Sullivan Brothers MSBA Marathon Fundraiser was held on Friday, April 14th at Boston Beer Works near the Boston Garden. The evening kicked off at approximately 7 pm, and by the time Brendan and I were cleaning up, it was 11:30. In the meantime, there were lots of smiles and cheers among all who attended this great annual event. The evening included free pool and appetizers, as well as our traditional silent and live auctions. The many great items people were able to bid on added some friendly competition to the evening's activities.

Both Brendan and I would like to thank all who attended for your continued support of our efforts and of the MSBA. Total proceeds for this year's fundraiser were $4,500.

EDITOR'S NOTE:

Three days after the Beer Works event, the Sullivan brothers took to the streets for the 110th running of the Boston Marathon. Brendan and Michael both ran the Marathon two years ago, as part of Team MSBA. Participating in the Mobility Impaired division, Brendan qualified to run again last year, but wasn't able to use his number due to an injury. He used the number this year instead, with Michael keeping up the pace and staying with him the whole way. Brendan and Michael, thanks for yet another Patriot's Day of keeping us cheering!

NEW TEAM MSBA MEMBER RAISES CASH AND RUNS FAST


Amy Fleming looks comfortable running!

The MSBA is so grateful to Amy Fleming, who ran this year's Boston Marathon on our behalf. Amy, who is a friend of Katie Packard and the Packard family, raised over $2,000 by running in our honor. She not only has impressive fundraising skills, she also finished in under 4 hours!

Thank you Amy for your kindness, generosity and dedication!!

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.

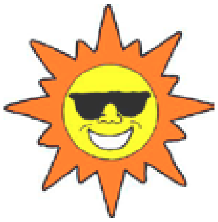
To be considered, or to nominate someone, please send a one-page letter, describing why the individual should be considered for this award to:

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

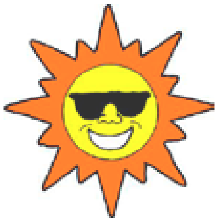
MARK YOUR CALENDARS FOR THE

FOURTH ANNUAL MSBA SUMMER PICNIC

SATURDAY, JULY 15, 2006



(RAIN DATE SUNDAY, JULY 16TH)



12:30 PM - 4:30 PM

AT DANEHY PARK

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

CAMBRIDGE, MA

PARKING LOT AND PICNIC AREA
NEAR THE OFFICE & RESTROOMS

MAP AND DIRECTIONS ON THE NEXT PAGE

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

**** PLEASE RSVP ****

If you know ahead of time that you will be attending, please let us know how many people you expect to bring with you, for planning purposes. Please RSVP to Ellen Dugan at edugan@msbaweb.org or to the MSBA Voice Mail, which is 888-479-1900. If your plans change last minute and you did not RSVP, feel free to join us anyway. If you need to confirm that we are using the Rain Date, call 888-479-1900 on the morning of the picnic.

BY PHONE: 888-479-1900 OR ONLINE AT www.msbaweb.org.

DIRECTIONS TO MSBA PICNIC:

DANEHY PARK SHERMAN STREET ENTRANCE

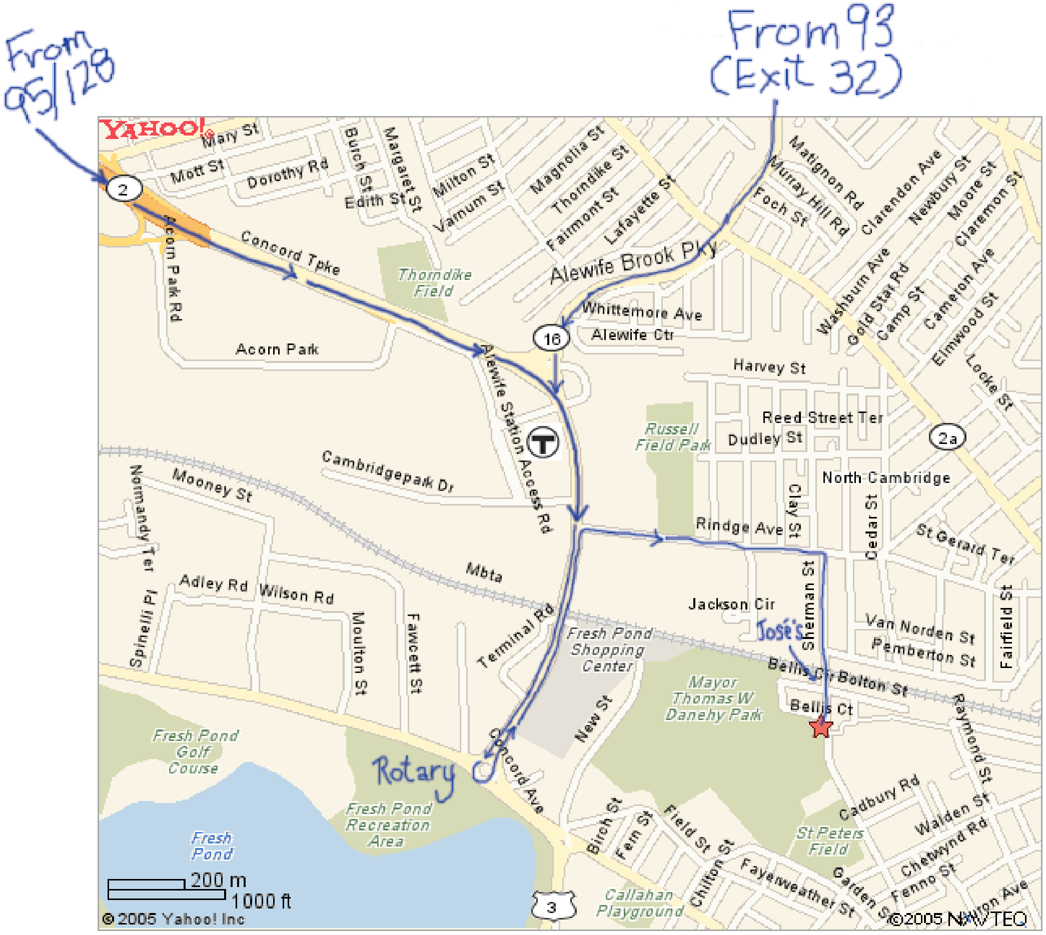
(99 SHERMAN ST, CAMBRIDGE, MA 02140)

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

From Route 95/Route 128 North OR South:
Take Route 2 EAST until it ends/splits. Stay right at this split. You'll see the Alewife (Red Line) T station on your right. Drive past the T station, then follow directions below **.

From Route 93 North OR South:
Take Exit 32 (Medford Square) and follow signs to Route 16 WEST – a long, winding stretch of road that changes its street name a couple of times. Don't be thrown by that. Stay on Route 16 until you reach its intersection with Route 2 at the Alewife T Station - a total of about 2.5 miles. When you see the T station in front of you, curve left, keeping the T station on your right. Then, follow directions below **.

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



YOU SHOULD GO TO CONFERENCE!

BY STEVEN NIEDZWICKI

My name is Steven Niedzwiecki. I am 29 years old, I live in Deerfield, Massachusetts, and I have spina bifida. I am writing this letter to encourage more of you to attend this years' national conference in Atlanta, Georgia to be held June 25-28, 2006 at the Omni Hotel in Atlanta. I have attended over 16 national conferences and have gotten a lot of good information from them about spina bifida.

Steve poses with a gigantic Twins shirt!

Last years conference was in Minneapolis and was especially exciting because some of the members of MSBA and a few of my friends that I have met at conferences got to go to a Minnesota Twins game. We watched the game from the Commissioner's Suite at the Metrodome. We all had a great time and the Twins won the game.

We had an adventure getting to the park too. We all had to get there on our own. We decided to use the taxi system instead of public transportation. Well, we all took different routes to the park and yes we all paid different fares. Some of us had very helpful drivers, others weren't so lucky. So, after the game, we all decided to take the train back and then venture the streets back to the hotel for the last leg of the trip. We all made it and have lots of fond memories. Thanks to my mother who worked hard to make this event happen.

I always look forward to going to conference, because it means seeing people that I haven't seen for a year. We always have such a good time, because that's the only time we get to see each other and conference time goes by so quick that I wish that it could be longer. I wish there was more time to do things with these great friends, even if it is just hanging out in the lobby until morning.

Of course, conference is much more than just hanging and having a good time. There are also meetings about the different aspects of spina bifida and the latest medial research into helping people with spina bifida live their lives to the fullest. I must admit that there have been big changes since I was born. They have started to have sessions that deal with things that young adults are dealing with.

I know that some of you might get bored with going to all the meetings, but there is always something to do at the conferences, whether it be catching up with old friends or getting out to see some of the local sights that every host city has to offer.

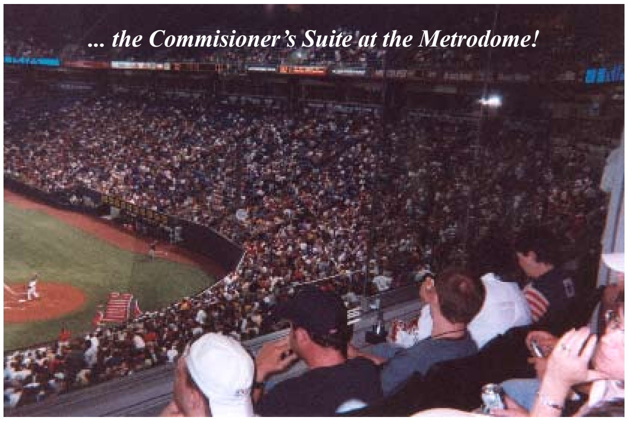
As an adult with s.b. or as a parent of a child with s.b. I would encourage you all to attend a conference. Once you attend one conference and see what it's like, you will look forward to the next and keep coming back.

I would also like to thank MSBA for their support in helping me attend these conferences. It is too late to apply for full benefits to this year's conference, but go on your own if you can. Otherwise, start planning now for next year!!

If you have any questions about travel, hotel or anything, even if it is not conference related you can reach me at sniedzwiecki@hotmail.com. — Steven

You get a great view of the field from ...

... the Commisioner's Suite at the Metrodome!



MSBA YOUTH & ADULTS GROUP

MSBAYA FOCUS: JAZZARTSIGNS & MORE

BY BRANDON SHANKS

After JazzArtSigns, Sax player Cercie Miller (back row, 2nd from left) and singer Lisa Thorson (front right) posed with MSBAers Robyn Hand, Brandon Shanks, Cori Couture, James Swanson, and Aimee Shanks.

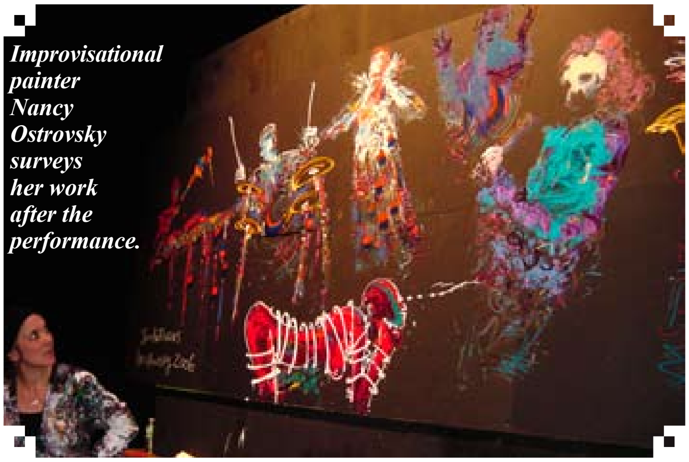
Going into Boston to celebrate the arts can be an adventure. Going to Boston to see JazzArtSigns was an unforgettable experience! Our crew from the MSBA Youth and Adults Group was in for quite a treat. Lead by singer Lisa Thorson, the night's performance included contemporary jazz music, visual improvisational painting, on-the-spot audio description, and interpretative sign language ... all at the same time. There was always something to watch, hear, feel, or - in short - experience! It was simply one of the most fun events I have ever been too.

Lisa and her gang really rocked (can you say that about a jazz concert?) with energetic, clever jazz giving homage to some of the great artists, like Thelonious Monk, Gershwin, and John Lennon. Along with the great music, two sign language interpreters were rapturous to watch. Accompanying one song's fast verbal scat,they moved from word to word in quick playful motions, then changed to expressive, almost tender gestures during dramatic moments. Meanwhile, beginning with a large — well huge really — black canvas on stage, and a paintbrush the painter's hand danced all night, creating surprising moments of color and image, and capturing the spirit of the evening.

One of the most memorable moments was midway into the night, Lisa asked the audience if everyone would bring wishes they'd written up to the stage. The band began playing a toe-tapping jazz base line, and Lisa began jazz singing, using our collected wishes as lyrics and improvising extensions of those thoughts in her own words. It was like watching our dreams dance before us in time to the music, as she sang phrases like:

> "I wish the world was flat … and there were no mountains or stairs or things to stop me from getting where I wanted to go."
>
> "I wish our leaders would learn to work together."
>
> "I wish we lived in a more dog-friendly world."

So next time JazzArtSigns is in town, you really should plan to go. It's a one-of-a-kind experience you really do not want to miss. This was one of the most accessible events any of us had ever seen and it's designed to be enjoyed by people of every ability. A special thanks goes out to Michele Scaramozza for putting this all together and to Wheelock Family Theatre for offering MSBAYA members a 50% discount on the tickets. The experience was unforgettable!!!



Improvisational painter Nancy Ostrovsky surveys her work after the performance.

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.

- June 3, 2006 **Parent/Adult Social** (12:30 pm - 4:00 pm), Children's Hospital, Boston, MA
- June 25-28, 2006 **SBAA Annual Conference, Atlanta, GA**
- November 4, 2006 (tentative date) **Lunch & Learn Day** Location TBA

UPCOMING MSBAYA EVENTS

The Jazz concert was a hard act to follow, but the MSBAYA Planning Committee hosted a Board Game Day on April 22, 2006 at Boston Children's Hospital. It was, as usual, great fun! We are currently working on our very first Parent/Adult Social to be held on June 3, 2006. This will be a great opportunity for parents to meet and to talk with adults who have spina bifida. To make this a success, we need both parent and adult participation. We are looking for a few parent volunteers to help get this concept off the ground. It is our intent to offer a few of these events throughout the year. We hope to host future events where kids with spina bifida can interact with the adults. If you are interested in volunteering to help, please contact Jen Kuhar at jkuhar@msbaweb.org.

We are also in the beginning stages of planning an MSBAYA Lunch and Learn Day, tentatively scheduled for Saturday, November 4, 2006. Details to be determined. If you have any ideas for topics for the day, or, know someone that may be interested in speaking, please contact any of the MSBAYA Committee members listed on this page.

As you can see, the MSBAYA Planning Committee is busier than ever. Watch your mailbox, the MSBA Web site and future newsletters for more details.
We look forward to seeing you soon!

MSBA YOUTH & ADULTS GROUP COMMITTEE

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Email: rlhand97@aol.com

Jen Kuhar
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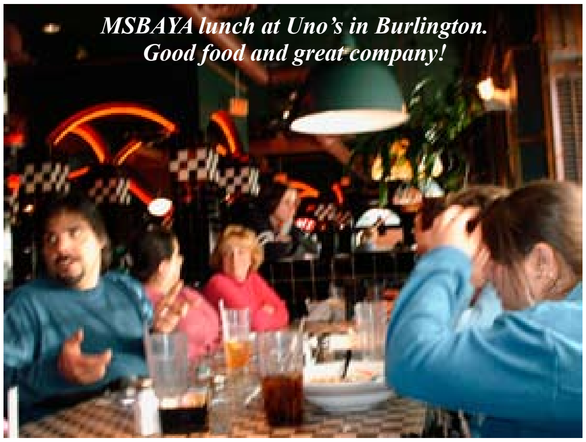
Email: jkuhar@msbaweb.org

Lindsay Meuse
Phone: 781-254-4925
Email: lmeuse124@aol.com

Aimee & Brandon Shanks
Phone: 508-587-6788
Email: orchid502@yahoo.com

MSBAYA Game Day. This time there was lots of Pictionary and Hangman!



MSBAYA lunch at Uno's in Burlington. Good food and great company!

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.

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.

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 mneal@msbaweb.org.

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 was accepted as an official charity of the Falmouth Road Race to be held on August 13, 2006. The MSBA was given 15 numbers. Participants will be required to raise $600 each to run for Team MSBA.
- The MSBAYA Planning Committee will be hosting a Parent Discussion Day for parents and legal guardians of individuals with spina bifida on June 3, 2006. Watch your mailboxes for more information.
- The MSBAYA Planning Committee will be working closely with the Picnic Committee to coordinate a scavenger hunt. The goal of this event is to have fun while getting to know each other. The picnic will be held on Saturday, July 15, 2006 (see more details on page 5).
- Hyacinth Bellerose and Jen Kuhar will represent MSBA at the Spina Bifida Conference in Atlanta as delegates.
- MSBA is looking into partnering with WMASS to assist them in raising funds to expand facilities at their Adaptive Snow School at Loon Mountain. The MSBA Board voted to fund the $15 membership fees for MSBA members to join Disabled Sports USA.
- The canister program is up and running. Please contact the MSBA if you are interested in placing canisters in businesses in your area.
- Ellen will have the New Parent packets together to be displayed at the Spina Bifida Association Conference in Atlanta.
- The MSBA will obtain an exhibit table at a Partners for Youth with Disabilities conference being held September 13-15, 2006.
- Effective after the June 4, 2006 Board of Directors meeting, Cori Couture will be resigning from the Board of Directors and from her post as newsletter editor.

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...):

____
____
____
____

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 in that family.

Annual Benefits Program

A qualified applicant may apply for up to $500 per year to enhance independence, increase mobility or otherwise improve his or 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. *Reimbursement*

   The Qualified Applicant must include receipts that show *payments already made* for eligible expenses. Once these receipts are received and reviewed, the MSBA will write a check payable to the applicant, parent, or guardian as reimbursement.

   OR

2. *Direct Pay*

   The Qualified Applicant must include a bill or invoice for eligible expenses that have not yet been paid. This application should mailed to the Board of Directors before any goods or services are provided. 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! Also, if you have questions, be sure to **CALL US!** Our number is: **888-479-1900.**

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**: ______________________

I am applying for:

___ **MSBA 2006 Annual Benefit of up to $500**

 ___ Receipts Attached

 ___ Make check payable to enclosed provider

→ __________ Amount Requested

** Below, please include an explanation of the benefit you are requesting and what it will be used for. Attach extra pages, if necessary. See previous page for details on proper documentation.*

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Please tear out this application form and return it to:

Ellen Dugan
MSBA Operations Associate
733 Turnpike Street #282
North Andover, MA 01845

The MSBA Board of Directors Is Looking for New Members

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

Copywriting/Editing
Finance
Graphic Design
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

WILLIAM G. KELLY OPPORTUNITY GRANTS

The William G. Kelley Foundation has announced that it is accepting applications from individuals and organizations for the first-ever William G. Kelley Opportunity Grants. These grants, in amounts of up to $1,000, are available to help individuals and families overcome physical challenges. Residents of Essex and Middlesex counties in Massachusetts may apply. The grants will be awarded based on physical and financial need, with priority given to applicants requesting assistance in the fields of assistive technology or universal design.

One $2,000 project grant will also be available to a nonprofit organization (in Essex or Middlesex county) that provides support to individuals with physical challenges. Projects aiming to foster inclusion of people with challenges through accessibility and universal design will be given priority.

Grant applications will be accepted on a rolling basis. There is no specific deadline.

For complete grant details, including a downloadable application form, please visit the foundation's Web site at:

http://www.williamgkelley.org/news_events.htm.

YOUR OLD WHEELCHAIR COULD BE THE FIRST FOR A CHILD IN BOLIVIA

BY GARY REIDISTER

Airline Ambassadors International (AAI), is a non-profit organization of airline personnel and others who use their travel benefits to bring humanitarian aid to children in need at home and abroad. Through AAI, my son Eric donated a wheelchair he had outgrown to Roberto, a boy in Bolivia. Roberto and his mom (shown holding a picture of Eric and his sister) were thrilled to receive this chair, which promises to greatly improve Roberto's quality of life.

Help AAI make a difference. There is a great need for the following equipment for children and young adults with disabilities:

Wheelchairs
Leg Braces
Walkers
Hearing Aids

To donate, please contact
Paula Moran, Regional Coordinator - Boston
Email: stonefelix@attg.net
Phone: 781-246-3163

Airline Ambassadors International Regional Coordinator for Boston, Paula Moran, with Roberto and his mother in Bolivia.

Founded in 1996 and recognized by the U.S. Congress and the United Nations, AAI has delivered medicine, medical supplies, school supplies, clothing, and food on missions to 44 countries and to children in 15 cities in the United States. In addition, they have escorted more than 1,000 children to receive medical care not available in their home countries.

For more information about Airline Ambassadors International, visit their Web site: www.airlineamb.org.

MEDICAL RESEARCH CORNER

SEXUAL ACTIVITY AND RELATIONSHIPS IN YOUNG ADULTS WITH S.B.

BY GINNY BRIGGS

Sexual activity and relationships for people with spina bifida has been a growing topic of interest in our community. To help address some of the issues that have come up in various group discussions, here are the results of a recent study on this tricky subject.

A Dutch study was published in 2005 reporting information on the sexual relationships and sexual activity of 157 young adults with spina bifida. The sample consisted of 41% male and 59% female, between the ages of 16 and 25, with an average age of 21 years. Each subject was interviewed individually about sex education, relationships, sexual activities, and sexual functioning. Some of the subjects explored were the perceived barriers to having sexual contact and relationships, and the amount of sexual experience of both males and females with s.b.

The study reported that although sex education had been provided to almost all patients, fewer than a quarter received information specific to people with s.b. Of all the subjects, 25% had a partner, 70% desired sexual contact, 47% had had sexual contact, and 22% had had sexual intercourse in the last year. Only 52% were satisfied with their present sex life. Incontinence and lack of self-confidence were important obstacles.

Sex education had been provided mostly by parents and schools, and only one fifth of participants had received information about sexuality issues from their physician. Many participants recommended that physicians and health professionals should take a more active role in giving information about sexual issues. Favorite topics for the participants were heredity of s.b, fertility, latex allergies and condom use, loss of genital sensitivity, incontinence, dealing with physical limitations in general, and questions of satisfaction with their bodies.

The 93 subjects who had never had sexual contact were asked what they thought the obstacles were. Incontinence and lack of self-confidence were most often reported, with no differences between young men and young women. Sexual functioning was also addressed, most often showing problems with orgasm and genital sensitivity in both genders. For males, this included sexual excitement, erection, ejaculation, and orgasm. For females, this included issues related to sexual excitement.

Some similarities were found in s.b. people who had had sexual contact. For example, young women were 2.4 times more likely to have had sexual contact than young men. People with IQ's over 70 were 3.2 times more likely to have had sexual contact and people who were continent were 2.2 times more likely.

This study referred to a previous study, in which men with s.b. understood that erectile dysfunction can be treated. The researchers felt that this was a good sign. It showed that it's important to discuss sexuality and options for treatment with patients who have s.b.

This study also showed that about one fifth of young women had reported unwanted sexual contact. (Other studies have reported even higher percentages.) They recommend a push toward greater awareness of this issue for the safety of all women with s.b.

This study concluded that issues relating to relationships, sexuality, unwanted sexual contact, fertility, and genetics are important to people with s.b. and that they should be discussed from an early age. Parents and caregivers should be aware that people with s.b seem to be less active in relationships and sexuality than people of the same age without s.b. Also, this population faces more problems concerning these issues than the general population. If families provide help at home and seek assistance from health care professionals, people with s.b. can get the information they need to have happy and healthy sexual relationships.

REFERENCE: Verhoef M, Barf H, et al. Sex education, relationships and sexuality in young adults with spina bifida. Arch Phys Med Rehabil, May 2005, v. 86, pg. 978-987.

***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.*

MORE THAN FOOT COVERINGS
WHAT TO LOOK FOR IN A WELL-DESIGNED SPECIALTY SHOE

BY HILORY PASTER

According to the Spina Bifida Association of America, an estimated 70,000 people in the USA are currently living with Spina Bifida. Everyday, an average of 8 babies are affected by Spina Bifida or a similar birth defect of the brain and spine. Each year, about 3,000 pregnancies are affected by these birth defects. A large majority of all ambulatory children and adults with Spina Bifida require some type of orthotic support—foot/leg brace/ankle-foot orthotic or adaptive shoes. So why have shoes been given so little attention?

In most cases, AFOs are individually cast, modified, and fit to the specific individual's needs as prescribed by medical personnel. Orthotists and physical therapists often think outside the box and explore available options that will help the child utilize most of his or her capabilities. The practitioners strive to assist the weak muscles, control abnormal muscle tone, improve alignment, and increase stability for these children. The ultimate goal is to enhance and improve the child's abilities to walk.

THE DAUNTING TASK

Once the prescribed AFOs have been made to the child's particular specifications, parents head off to search for shoes. Thus, the daunting task begins. Parents expend great effort as they search for shoes that are deep enough, long enough, and wide enough. The search all too often results in purchasing shoes a size-and-a-half to two sizes larger than the natural foot to satisfy the demands of the othotics.

Sometimes parents modify the child's shoe by tearing and cutting parts of the shoe to fit the AFOs. This has typically resulted in buying shoes that may actually adversely affect the functioning abilities of the child. With the best of intentions and without meaning to, parents have thus undone what practitioners and medical professionals have strived so hard to achieve.

After decades of little or no attention paid to pediatric specialty footwear, some standard shoe designers have begun to listen to the need for additional width and on occasion families can find a product designed as an extra-width shoe to assist with accommodating braces. However, don't be fooled: width alone will not provide the correct fit.

A properly designed shoe must have a depth that will enable the hinges, posterior stops, and/or Velcro straps to sit well below the heel counter. The shoe should securely support the brace and not breakdown or collapse from its pressure. Standard shoe manufacturers have attempted to address this critical component with adjustable depth insoles, which allow the individual to accommodate the amount of depth needed for a precision fit. However, insoles are slightly misleading. A shoe that has more than one insole does not necessarily mean that it is deeper and will accommodate the AFO. It's necessary to take a good look at how much depth is actually gained upon removing the insole and what happens to the integrity of the shoe once the insoles are removed.

THE INSIDE STORY

Exposing the natural internal sole of the shoe will tell you a great deal about the manufacturing quality of the product. Look for a smooth surface that is free of glues, rough spots, or exposed materials that can cause abrasions, breakdown, and discomfort. Closely examine the shoe to see what role the insoles play in creating a firm, supportive cavity. The support and strength of the shoe should be provided by the quality of the materials and construction, not by the use of the insoles.

Pay close attention to the materials used in manufacturing the shoe. Unfortunately, the "typical" shoe manufacturer cannot address the specifics of specialty shoe design; most off-the-shelf shoes are not created for children with toe drag, scissoring, or challenging gait patterns. Such children wearing standard shoes go through them like a knife through butter and many families need to purchase shoes once a month because soles wear out, linings tear, and support breaks down. Only when a shoe is designed specifically with children's adaptive footwear needs in mind will it be durable and enhance the effectiveness of the orthotic.

Here are some elements to look for in choosing a specialty shoe:

- Internal engineering with adjustable depth technology
- Wider heel and toe box that accommodates the orthosis without compromise
- Distinctive sole with increased contact surface to promote greater medial/lateral stability
- Ankle-to-toe speed lacing with locking eyelets for faster on-off and ease of wearability
- Geometrically graded last that ensures precision fit
- Fray-resistant lining and high abrasion-resistant toe cap to ensure durability

Last but not least, children who need specialty shoes want to be as fashionable as their peers. Just because a shoe fits an orthotic does not mean it has to be unattractive or clunky. Some companies, such as KeepingPace, offer contemporary fashion and stylish looks as well as well-engineered design.

It has become apparent, that there has been a long standing, pent up demand for innovatively designed, affordable specialty footwear products addressing the pediatric market. Children with orthopedic disabilities need solidly designed footwear that can accommodate their adaptive devices and are easy to use. Fortunately, the search is no longer such a daunting task.

Hilory Paster is Vice President Sales and Marketing for KeepingPace, Inc., a manufacturer of specialty footwear in Gloucester, MA. She can be reached at 888-526-0020 or by email at footwear@keepingpace.com.

KEEPINGPACE

MSBA Canister Program

Thanks to Anthony and Susan Leo from the TStop Superette in Lynn. By displaying an MSBA canister on the counter at their store, they raised $700 for our organization this year alone. The Leos have been helping us out this way for years, and now you can too.

The MSBA has set up a streamlined, simple program for getting collection canisters into more stores. Participating in this program can even help *you* get extra benefits toward attending the SBAA's Annual Conference next year!

To learn more about the MSBA Canister Program, please email our Operations Associate, Ellen Dugan at edugan@msbaweb.org, or call the MSBA Voice Mail at 888-479-1900.

Donations & Special Contributions

In Memory of *Dr. Gilbert Bellerose*:

- Mr. & Mrs. Sam Clark of Kennebunk, ME

In Memory of *Thomas O'Toole*:

- Thanks to Ms. Meg Brown
- Mr. & Mrs. Francis Crosby of Dorchester, MA
- Mr. & Mrs. Michael Corliss of Quincy, MA
- Mr. & Mrs. Thomas Flemming of Marshfield, MA
- Ronald M. Chiuve and the North Reading Youth Athletic Association
- Mr. & Mrs. Kevin Lemieux of North Reading, MA
- Mr. & Mrs. John Healey of Holbrook, MA
- Mr. & Mrs. Robert Pereira of Georgetown, MA
- Mr. & Mrs. Anthony Brandano of North Reading, MA
- Mr. & Mrs. Frederick Rooney of South Boston, MA

MSBA Member Donations, Winter / Spring 2006

- Mr. & Mrs. Brian Finn of Townsend, MA
- Mrs. Mary-Ellen Raymond

Special Thanks to:

- Massachusetts Lodge of Elks Plymouth Lodge
- Massachusetts Lodge of Elks Orleans/Eastham Lodge

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

- The following website was recommended by one of our contributors:

  MULTI-CULTURAL INDEPENDENT LIVING CENTER OF BOSTON, INC.

  Visit their Web site at: http://www.milcb.org. MILCB has the following mission: "Empowering disabled people to lead independent and productive lives through education and advocacy." One small part of the Web site includes an Advocacy area where you'll find a link to federal and state laws regarding placards, airlines, sales tax, and more.

- **BAYLIE FOR BRAINS**

  Baylie Owen is a six year-old girl from Houston with a very big heart! She also happens to have a Chiari Malformation (common in, but not exclusive to, kids with spina bifida). This little girl has raised just under $100,000 by making and selling bracelets to help fund research on Chiari Malformation through the University of Chicago. She started by selling drawings and gave her neurosurgeon, Dr. Frim, $27.00 to help her friend who gets headaches. The latest check was for $70,000. It is wonderful to see a little girl who goes beyond her own significant issues to help others. It is also wonderful to see funding of research that can help spina bifida as well. Check out Baylie's Web site at http://www.baylieforbrains.com.

Six year-old Baylie Owens models some of the bracelets she's made to raise money for Chiari Malformation research.

- **SUMMER CAMPS**

  If you are looking for a summer camp, have a look at the listings on the MSBA's Web site: http://www.msbaweb.org.

- **BOY SCOUTS**

  My 11-year-old joined Cub Scouts a few years ago and has just become a Boy Scout. We have not tried overnights yet, but the meetings, day camps and the other events have been very open to children with disabilities. I have found the parents and children to be very supportive and more accepting than the general population. My son has learned science, ecology, morality, and how to enjoy the outdoors in a hands-on manner. My son is a sports fanatic but is not able to participate in a fulfilling way with his friends. At scouts, he is just one of the group. Check out http://www.scouting.org, and consider trying our your local troop in the fall. It could be worth visiting a few meetings to see if the leaders and the boys are as enthusiastic as ours have been!

__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.

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 CALENDAR OF EVENTS

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.

Date	Event	Location
May 15, 2006	MSBAYA Planning Committee Meeting	TBD
May 31, 2006	Jean Driscoll Scholarship Application Deadline	See page 4
June 3, 2006	Combined MSBAYA & MSBA Parents Event	Children’s Hospital, Boston
June 24, 2006	SBAAYAA Adults Day (Pre-conference Event)	Omni Hotel, CNN Center, Atlanta, GA
June 25-28, 2006	SBAA Annual Conference, Atlanta, GA	Omni Hotel, CNN Center, Atlanta, GA
July 15, 2006	MSBA Annual Summer Picnic (12:30 - 4:30 pm)	Danehy Park, Cambridge, MA
November 4, 2006	MSBAYA Lunch & Learn	TBD
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 msbaparents@yahoogroups.com.

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

Massachusetts Spina Bifida Association

733 Turnpike Street, #282
North Andover, MA 01845

Phone: 888-479-1900

Web site: www.msbaweb.org

Summer Newsletter Deadline

July 28, 2006

Please submit articles and information for publication to:

MSBA News
733 Turnpike Street #282
North Andover, MA 01845
Email: edugan@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.