MSBA NEWS

A PUBLICATION OF THE
MASSACHUSETTS SPINA BIFIDA ASSOCIATION

MEMBER, SPINA BIFIDA ASSOCIATION OF AMERICA

- FALL 2005 -

INSIDE THIS ISSUE

MSBA Membership & Benefits

LETTER FROM THE PRESIDENT

BY BRIAN PACKARD

Hello again to a waterlogged MSBA. I hope each of you has escaped the drenching rains the fall season has brought with it. It is a sobering reminder of nature's devastation we have all witnessed these last few months around the world. I have been very proud to witness our national organization's reaction to Hurricane Katrina, launching the **SB HELP** (Hurricane Emergency Life-support Program) to support people with Spina Bifida in the Gulf Coast in the wake of this tragic event. Through SB HELP, the Spina Bifida Association has matched donated medical supplies and services with s.b. families throughout the affected region. Our heartfelt thanks go out to those of you who donated supplies and other critical items to our friends in need.

Closer to home, the MSBA has been very active in distributing benefits funding to dozens of families in our area, helping to cover expenses from catheters to home accessibility projects. We are grateful to be able to extend financial assistance to those in need. Please see pages 12 & 13 for information about the **MSBA Benefits Program**.

As the MSBA continues to grow and reach our long-term goals, the Board is pleased to announce that we will be hiring an **Operations Associate** to coordinate and streamline our efforts. This part-time employee will provide day-to-day administrative support for the MSBA Board of Directors, manage projects and be responsible for the smooth daily operational activities of the organization. From bookkeeping to organizing social, fundraising and educational events, the Operations Associate will be an important asset to help fuel our ongoing progress.

Please join the Board at our **Annual Meeting**, to be held Monday, November 7th at the Centres at Burlington. At the meeting, we will review some of the recent progress the MSBA has made in the core areas of our Strategic Plan, discuss future priorities, review our Bylaws and hold our election of Officers. Board meetings are always open to members, but the Annual Meeting should be a wonderful opportunity for members to experience the workings of our organization.

For a slightly more festive gathering, mark your calendars for the **Spina Bifida Research Fundraiser** hosted by MSBA members, the Foti Family. This evening of dinner and dancing will benefit the MSBA and Children's Hospital Boston. The event will be held at the Danversport Yacht Club on Saturday, November 12, 2005 at 7:00pm. The cost is $55.00 per person and tickets are going fast. See page 18 for more details.

Also, please save the date for the **MSBA Annual Holiday Party**. This year, it will be held on Sunday, December 4th, from 12:30 -5:00 pm, at the Hampton Inn in Natick. See pages 3-5 for more details. Big thanks to Jen Kuhar for coordinating the event!

I hope you all have a great fall season. Enjoy the leaf-peeping, football and cider. I wish each of you health and happiness.

— Brian Packard

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ARNOLD CHIARI INFORMATION
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67 Spring Street, Weymouth, MA 02188
Also try World Arnold Chiari Malformation Association at
http://www.pressenter.com/~wacma/

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CANISTER COLLECTIONS
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Email: jenkuhar@msn.com

FUNDRAISING
Hyacinth Bellerose 978-649-8724
33 Forest Street, Dunstable, MA 01827
Email: bellerose33@charter.net

LITERATURE & LENDING LIBRARY
Danielle Everett 781-826-4485
21 Elm Street, Pembroke, MA 02359

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Ginny Briggs 508-460-7647
Email: ginnybriggs@yahoo.com

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Matt Neal 508-460-7647
Email: matt_neal@verizon.net

MEMORIAL DONATIONS
733 Turnpike Street, #282 978-683-6644
North, Andover MA 01845

PARENTS HELPING PARENTS
Cara Packard 978-683-6644
178 Hay Meadow Road, North Andover, MA 01845
Email: packard44@comcast.net

PUBLIC AWARENESS / PUBLICITY - VOLUNTEER NEEDED

YOUTH & ADULTS GROUP
Michele Scaramozza 339-927-7227
Email: mozzas@comcast.net

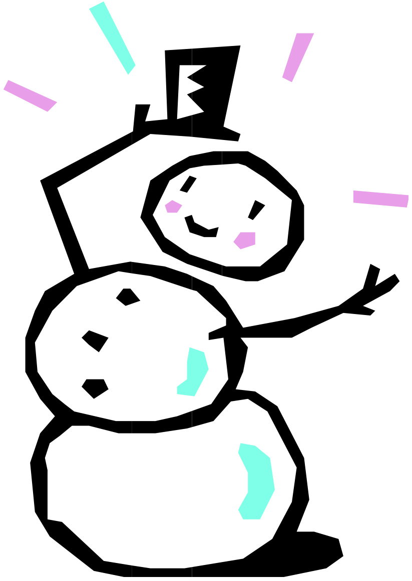
WHEELCHAIR SPORTS
Dick Crisafulli, Mass Hospital School 781-828-2440

Mark Your Calendars for
the 2005 MSBA Holiday Party!

Sunday, December 4, 2005 from 12:30 pm- 5:00 pm
at the Hampton Inn, Natick

** Directions on back of this page **

Please cut out the whole page, and bring it with you!



Party will include:

- Lunch
- Fun and Games for all ages
- Special Holiday Guest
- Coloring contest for kids (see below)
- Yankee Swap for adults* (bring a wrapped gift worth no more than $10)

*Adults with s.b. do not need to bring a Yankee Swap item.

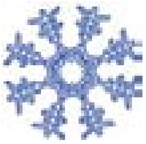
****** Please RSVP by Tuesday, November 22, 2005 ******

by Email: **jenkuhar@msn.com**

by Phone: **508-620-3963** or

online at **www.msbaweb.org**

Include the Following Information in Your Reply:



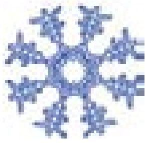
• Your First and Last Name •

• Your Phone Number •

• How many people in your group •

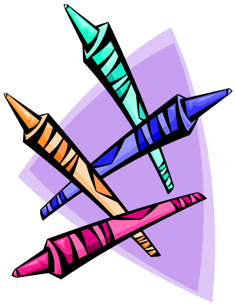
• Names and ages of everyone in your group •

• Please specifiy the name of the person with s.b. •



Kids - break out the crayons and start coloring! You could win a prize at the MSBA Holiday Party!

(See Page 5 for coloring page & contest mailing info.)



Holiday Party Details

(Cut out this page and stick it on your fridge, so you'll have it on December 4th!)

LOCATION: ***The Hampton Inn***
319 Speen Street, Natick, MA 01760

TIME:
12:30 pm - 5:00 pm

PHONE:
508-653-5000

DIRECTIONS

From the North

- Take Interstate 95 (Rte 128) South to the Mass Pike (Interstate 90) West.
- *THEN* Follow Directions in Box Below***

OR

- Take Interstate 495 South to the Mass Pike (Interstate 90) East.
- *THEN* Follow Directions in Box Below***

From the South

- Take Interstate 95 (Rte 128) North to the Mass Pike (Interstate 90) West.
- *THEN* Follow Directions in Box Below***

OR

- Take Interstate 495 North to the Mass Pike (Interstate 90) East.
- *THEN* Follow Directions in Box Below***

From the East

- Take the Mass. Pike. (Interstate 90) West.
- *THEN* Follow Directions in Box Below***

OR

- Take Route 9 West to the Mass Pike/Speen Street Exit.
- Stay in the right hand lane through the lights.
- The Hampton Inn is on your right.

From the West

- Take the Mass Pike (Interstate 90) East.
- THEN Follow Directions in Box Below***

OR

- Take Route 9 East to the Mass Pike/Speen Street Exit.
- Stay in the right hand lane through the lights.
- The Hampton Inn is on your right.

***

- Stay on the Mass Pike to Exit 13 (Framingham/Natick).
- Go through the toll booths and bear left after you leave the toll plaza.
- Upon exiting the ramp, you will be on Route 30 East.
- Continue to the first set of lights, and turn right onto Speen Street.
- Go straight through the first set of lights.
- As you approach the second set of lights, make sure you are in the far left lane as you go through the light.
- You will see a brick building on your left.
- Turn left onto Superior Drive (before Sam's Club).
- You will see the Hampton Inn at the next intersection, across the street.

Once You Arrive to the Hampton Inn: Go in the main entrance and take the lobby elevator to the second floor. We will be in the Plymouth Room.

2005 COLORING CONTEST

Hey, Kids, color the picture below, fill in your name and address, and send it to us at the address below. You could win a great prize at the MSBA Holiday Party on December 4th!

Name: ____________________
Age: _____
Address: __________________
____
____

Mail Your Entry to:

Massachusetts
Spina Bifida Association
2005 Coloring Contest
733 Turnpike Street, #282
North Andover, MA 01845

Elli Meeropol:
A Look Back as She Moves Forward

By Cori Couture

As mentioned in the last issue of the MSBA News, Elli Meeropol has left her position as a Pediatric Nurse Practitioner* at the Shriners Hospital in Springfield, MA. In fact, she has made the transition out of medicine altogether, in favor of the "civilian" life of a novelist. We decided to take this opportunity to ask Elli to share some of her observations about medicine, spina bifida, and how things have changed since she began working in this field.

CAN YOU GIVE A BRIEF TIMELINE OF YOUR WORK?

I came to Shriners Hospital in 1981 from a pediatric intensive care unit in Oakland, California. I was hired to staff the Intermediate Care Room and to develop a pre-op teaching program. About two years later, my role shifted to nursing staff education, and in the mid-1980's I worked part-time at the hospital while I attended graduate school in Child and Adolescent Health. As a Clinical Nurse Specialist I started focusing more in the outpatient clinics, and that's when I started working with the urologists, helping families manage neurogenic bladder and bowel programs and doing the urodynamic studies. In the mid-1990's, I returned to school again and became a Pediatric Nurse Practitioner. At that time, I joined the Medical Staff of the hospital, seeing patients in both orthopaedic and urology clinics.

WHEN YOU STARTED IN MEDICINE, WAS MYELOMENINGOCELE YOUR MAIN FOCUS OR DID THAT DEVELOP LATER IN YOUR CAREER?

I became interested in spina bifida the first year I worked at Shriners Hospital. It was because of one little girl. She was about 6 years old at the time, in for hip surgery and she was a fighter, so feisty. Her Mom was a fierce advocate for her. I was so impressed by them that I wanted to learn more about spina bifida and to get more involved.

As I learned about the condition and began to understand the challenges presented to my patients' self-esteem, I became interested in the emotional issues as well as the medical ones. In particular, I saw some young girls struggling with early puberty, one more way they were different from peers. To provide peer support and discussion, a social worker and I started a support group for school-aged girls that met during spina bifida clinic.

HOW HAVE THINGS CHANGED (POSITIVE AND NEGATIVE) SINCE YOU STARTED IN MEDICINE, AND SPECIFICALLY IN WORKING WITH SPINA BIFIDA?

POSITIVE

Improvements in medications and surgeries have made a big difference in the treatment of issues like continence. Bowel and bladder management – both preventing serious disease and improving continence – can have so much impact on people's lives.

The move toward *Evidence-Based science*, basing treatment recommendations for spina bifida on scientific studies, offers great advantage. In 2003, the Spina Bifida Association of America hosted a conference entitled "Evidence-Based Practice in Spina Bifida: Developing a Research Agenda". This helped to focus attention where our knowledge is most inadequate and to guide formal studies currently under way or in development.

An example of an evidence-based research study is the MOMS Project (Management of Myelomeningocele Study), which is being conducted by the National Institute of Child Health and Human Development (NICHD), a part of the National Institutes of Health (NIH). This controlled clinical trial is designed to determine whether prenatal surgery or postnatal surgery is the better way to "manage" (treat) myelomeningocele by comparing how children do after the two approaches.

Strength of Leadership at the national level. The SBAA has become a much stronger organization over the past several years. They have increased their efforts around advocacy and policy-making on Capitol Hill in amazing ways. I think that the Cindy Brownstein (Executive Director of the SBAA), the national office and staff are doing a fantastic job.

NEGATIVE

Regionally, we've lost some ground. While individual state spina bifida chapters are strong, there seem to be fewer regional networking and conferences to complement the national one. Many families can't afford to attend the national conference. If there aren't local or regional meetings, people may lose out on important educational opportunities.

Fewer s.b. clinics. Over the last ten years, several multidisciplinary spina bifida clinics in the Northeast have dissolved, and we have fewer nurses to help people and families coordinate care and offer ongoing support and education around the condition. There are dedicated individuals out there, intent on providing high-quality services to people with spina bifida, however this is expensive and our society doesn't appear to value it highly.

YOU HAVE BEEN AN ESPECIALLY PASSIONATE SPEAKER AND WRITER ON THE TOPIC OF LATEX

Allergy. Why and how did you develop your interest in this area?

In June of 1989, I attended the quarterly meeting of NEMA, the North East Myelodysplasia Association, an organization of parents and health care professionals working with people who have s.b. A member brought our attention to a recent article in the New England Journal of Medicine. It was written by Jay Slater, MD and reported on anaphylaxis to rubber during surgery in two or three children with spina bifida. When we read this article, we had a group "Eureka" moment. We had all seen patients react to latex catheters and gloves, but until that moment, none of us put it all together as a potentially serious allergy.

At this meeting, we saw an opportunity and mobilized very quickly. NEMA members developed a questionnaire about latex reactions, surveyed our patients and found that about 20% had a history of these reactions, and published the results in a letter to the same medical journal.

Over the next few years, there was an avalanche of information about latex allergy, which frequently affects health care providers as well as patients. It was a fascinating topic to study, and it was exciting to be learning about a new condition and teaching patients with spina bifida and their families how to prevent harm. It was eye-opening too, because many people in the medical community continued to refuse to hear this information. I had the opportunity to attend national and international conferences and bring new information back to our community.

If you could cure or remove one aspect of spina bifida, what would it be?

Bowel incontinence. Dealing with this issue is so difficult, so distasteful to many families that they put it off for too long. Bowel incontinence can be managed successfully. But if ignored… Well, there are fewer things more socially devastating that having a bowel accident.

Do you have any advice for new parents of a child with s.b.?

There's not just one correct way to raise a child with spina bifida, any more than one right way to raise any child. Families have different strengths, different beliefs and values. There are many different routes. Mostly, I wish each family could have the resources they and their child will need to grow up healthy, and the support of a respectful and knowledgeable team of health providers to make the journey with them.

What has been the best part of your medical career?

Latex allergy work. In terms of intellectual challenge, of seeing a problem and figuring out ways to attack it and make it better, my work around latex allergy and spina bifida has been particularly rewarding.

Helping families deal with bowel and bladder issues. I never planned to be a "pee and poop nurse" but by becoming a nurse practitioner and specializing in neurogenic bowel and bladder, I felt like I made a difference. These issues are not the most glamorous, but they have probably been the most satisfying part of my work.

S.B. Communities. The families, support organizations, and medical professionals involved with spina bifida are an extraordinarily welcoming community. Perhaps it's because SBAA is run by the people affected, rather than by professionals, that there is less hierarchy and we all work together.

It has been an incredibly satisfying career

What will you miss the most about leaving your medical career behind?

I will miss knowing what's happening with my patients. You get to hang out for years and years with families. I will miss the ongoing contact. I will miss being part of their lives.

Tell us a little bit about where you are going from here.

I started writing fiction, short stories and novels, about six years ago. I love it! In January, I will complete a two-year, low-residency graduate program and receive my Master of Fine Arts from the Stonecoast Creative Writing program at the University of Southern Maine.

My job then is to finish revising the novel I'm working on, and try to get it published. Since one character in this story is a 5 year-old with spina bifida, I am not leaving spina bifida behind. I think about it every day.

After nearly than 30 years in medicine and nearly as many working with patients who have spina bifida, Elli has had an enormous impact on inumerable families from Massachusetts and beyond. We know she will be sorely missed. The MSBA wishes her all the best of luck in her new career!

SBAA Conference 2006: Start Planning Now!

The Minnesota conference was a success for both content and MSBA attendance.

The **SBAA's 33rd Annual Conference** will be held **June 25-28, 2006 in Atlanta, Georgia** at **The Omni Hotel, CNN Center.**

Hotel Details

The luxurious AAA Four-diamond Omni Hotel at CNN Center is located in the heart of downtown Atlanta, within the CNN Center Complex. Situated across from Centennial Olympic Park, connected to Philips Arena and the Georgia World Congress Center, it is the closest hotel to the Georgia Dome. The hotel is also just 15 minutes from the Atlanta Hartsfield International Airport.

Basic Costs

Hotel Rooms: The rack rate for each room is over $250.00 but, once again, the SBAA has negotiated the nightly rate to $125.00.

Flights: Right now, a round trip **nonstop** flight from Boston to Atlanta is only $271.00. From Manchester, NH it's $342.00.From Providence, RI: $322.00. From Hartford, CT: $322.00.

Watch the next newsletter for more info on Atlanta. Also, check out pages 12-13 for details on the **MSBA Conference Benefits Program**, through which you can get **up to $1,750.00 to attend conference!**

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* In the Summer issue of the newsletter, two errors were made in the announcement of the award Elli received at Conference. She is not the Nurse Coordinator of the Shriners Myelo Clinic, but rather a pediatric nurse practitioner. Also, the award she received was not the Lifetime Acheivement Award, but the Chair's Excellence Award. Apologies to Elli for the misprints.

** SBAA ANNUAL CONFERENCE 2005 –

A TRIP TO MINNEAPOLIS

BY DAVE BAKER

This year was Jordan's first SBAA Conference. Jordan is our five-year-old daughter, and she was accompanied by her grandmother (Nanny, my mom) and me. My wife, Melissa had been to the previous two conferences, meeting some great people and learning quite a bit from the sessions and tapes she brought home. With two other children (3 years and a newborn), taking the whole family seemed like more adventure than we could handle this year. So, Melissa stayed home with the other kids, while Jordan, Nanny and I went off to Minneapolis.

Jordan was extremely excited about taking the trip. Of course, that had a lot to do with having Nanny all to herself for four days. We got in a day early and spent the time with some friends who live in the area. They took us to the Mall of America, where we met a few people from the conference, including a six-year-old boy and his parents.

Once the conference started, I watched as Jordan realized, and started to pay attention to the fact that there were other kids and adults there who had spina bifida too. It was really the first time she had had that experience, and it was interesting to watch her reaction. For the most part, she took it in stride, which was great to see. She became more conversational, and at one point, wheeled up to a man in a chair and started talking to him. After a few other questions, she asked if he had spina bifida. He explained that he did not, but had been in an accident a long time ago. She was very curious, and double checked with him a couple of times to make sure he really didn't have spina bifida!

Jordan was registered for Kids Camp, which was very well run and organized. A lot of the kids seemed to have a great time. In spite of that, for Jordan, it was tougher than we had hoped. The plan was that Nanny would be around Jordan as much as needed to make her feel comfortable. (Nanny is a kindergarten teacher and is fantastic with kids in a setting like that.)

At the time, Jordan was only four-years-old, and had never attended anything other than half-day preschool where her aide was someone very familiar to her. In this setting, a young girl was assigned to be her aide and the folks running KidsCamp told us that they did not want either of us to stay with her. I saw their point, in terms of encouraging the kids to develop independence, but I think it greatly detracted from the experience for Jordan. She seemed to have an okay morning, and we came back and ate lunch with her. However, when I arrived to get her at the end of the day, she was lying down in the nap room, had been crying, and I've never had her grab me so tight and not let go when she saw me. She didn't want to go back the next day at all, but I finally got her to agree to go for a few hours in the morning as long as we could all go to lunch together and spend the afternoon doing something fun.

As a result of these negotiations, my time for attending conference sessions was a bit limited, but I still was able to get to a few. My favorite was a session led by Dr. Richard Horowitz on fathering in a family with special needs. It was a "fathers-only" session, and included everyone sharing their "best" and "worst" things about having a child with spina bifida. Dr. Horowitz shared some insightful commentary and helpful facts that have I referred back to on several occasions since the conference.

That session in particular helped me to understand that other fathers take joy from, and struggle with, many of the same things my wife and I do. My hope is that Jordan was able to take away a similar understanding as she met, talked with, or even just observed, the other kids and adults at the conference.

To any family that has never attended the conference, I absolutely recommend making the trip. It is educational, inspiring, and a lot of fun for everyone. As Jordan says, "Minneapolis was fun, can we go back there some time?

Hey, maybe next time we should go to 'Mickey-apolis' – ha ha ha!

Dave Baker and his family live in South Burlington, Vermont and are members of the MSBA. Dave can be reached at dsbaker@adelphia.net.

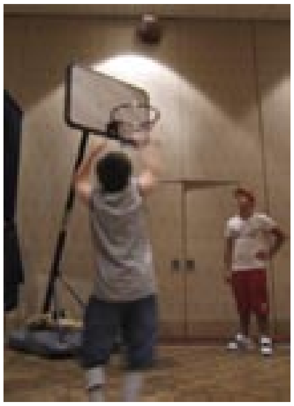
– More Stories from Minneapolis **

Conference — A Child's Perspective in Words & Pictures

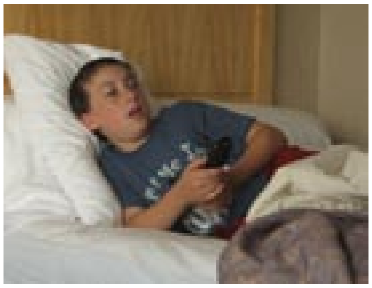
By Nathan Bellerose

My name is Nathan and I'm 10 years old. This year was my third year going to Kids Camp at the spina bifida conference.

This year was kind of special because it was just my mom and me. My sister Sophia stayed home with my dad and nana! Kids Camp is always fun, especially the basketball.



We also got to eat out all the time, lay in bed and watch TV, go to a video arcade and visit the Mall of America.



We had a LONG wait at the airport but the view was great on the way home.

I must say that I was happy to play with my sister when I got home.

I am getting to know some of the other kids and the teenagers that play with us. I hope we go again next year wherever it is. You should come too!!!

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 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. (See page 12 for more details.)
- 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 mattneal@alum.mit.edu .

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 9:00PM. All members are welcome to attend. If you are interested in attending a meeting or have any issues or concerns to be brought up at a meeting, please contact any one of us.

- The Board solidified its benefits policy for the 2006 SBAA Conference being held in Atlanta, GA in June 2006. Further details are inside this newsletter.
- The ad for the Operations Assistant has been posted on Craig's List. The Hiring Committee members are Ginny Briggs, Hyacinth Bellerose, Cori Couture and Brian Packard. It was decided not to pursue office space at this time.
- The MSBA Holiday Party will take place on Sunday, December 4, 2005 at the Hampton Inn in Natick from 12:30-5:00PM.
- The MSBA Board voted to postpone its Annual Meeting from October 3, 2005 to November 7, 2005. This meeting is open to the public.
- As mentioned in the summer newsletter, Brendan Sullivan is stepping down from the Board of Directors. However, he has agreed to continue in his role as the MSBA Treasurer.
- Matt Neal has made progress on redesigning the MSBA database.
- The Mason Rice School (Newton, MA) playground project is complete.

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

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.

WHAT 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 Membership, unless there is more than one person with spina bifida covered under that Membership.

ANNUAL BENEFITS PROGRAM

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

A Benefits application must be submitted, in writing, *to the MSBA Benefits Coordinator* (Cara Packard), by the Qualified Applicant or their parent or guardian via postal mail or email. The application will be reviewed for approval at the following month's Board of Directors meeting. Once the application has been approved, there are two ways for a Qualified Applicant to receive Benefits funds:

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

   OR

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

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**: ____________________

YOURS FOR FREE!

___ **MSBA Annual Benefit (Level 1)** **$500**

Get $500 Annual Benefit just by applying.*

$500 → ____________

PLUS

___ **2006 Conference Benefit (Level 2)** **add $250**

Add $250 to your total (for Conference Expenses) just by applying.

$250 → ____________

PLUS

WORK FOR YOUR BENEFITS

___ **2006 Conference Benefit (Level 3)** **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 Beerworks Fundraiser.
- Place and monitor 5 collection canisters in local businesses.

$500 → ____________

OR

___ **2006 Conference Benefit (Level 4)** **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
- Bring 10 paid attendees to the Boston Beerworks Fundraiser.
- Place and monitor 10 collection canisters in local businesses.

$1,000 → ____________

CONFERENCE BENEFITS

GRAND TOTAL 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 and 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 it will be used for. Attach extra pages, if necessary. No particular format is required.*

____

____

____

____

Please tear out this application form and return it to:

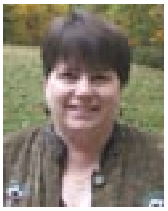
Cara Packard
MSBA Benefits Coordinator
733 Turnpike Street #282
North Andover, MA 01845

WHO'S OUT THERE?

(MSBA MEMBER SPOTLIGHT)

THIS MONTH'S FEATURED MEMBERS:

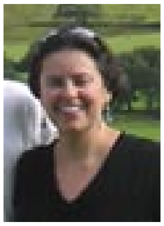
YOUR *ALL VOLUNTEER* BOARD OF DIRECTORS & OFFICERS



HYACINTH M. BELLEROSE, DUNSTABLE, MA (Vice President, Board Member) Hyacinth, and her husband Marc Bellerose, are both attorneys (real estate and family law, respectively) but work primarily at the beck and call of their children Nathan (age 10, sports fan extraordinaire, s.b. level L5 - S1) and Sophia (age 5, princess ballerina). Hyacinth joined the MSBA to meet local families connected to s.b. At the time, the MSBA was going through a rough patch. Hyacinth credits the President at that time, Paul Constantino, with keeping the organization in tact. Now, 6 years later, Hyacinth and her family have met and grown with almost 100 families affected by s.b.. She sees our incredibly energetic current President, Brian Packard, as the driving force behind the MSBA's recent growth ongoing development into a true 21st century entity. Developing according to a recently published Strategic Plan, holding significant fundraisers and relying heavily on email and a new web site, the MSBA has a strong basis but, most importantly, has maintained the social and personal contact important to the heart of our organization. Hyacinth is proud to be a part of this new MSBA and encourages families and individuals to get involved. Just attend one event and we bet you will return for another!

GINNY BRIGGS, MARLBOROUGH, MA (Board Member) lives with her husband and fellow Board Member Matt Neal and their two children, Grace (age 5, s.b. level S1-S2) and Andrew (age 7) in Marlborough, MA. Ginny joined the Board 2-1/2 years ago to meet other families affected by s.b. and to become more involved in the s.b. community. She is very excited to begin working on establishing an adult spina bifida clinic in conjunction with Children's Hospital in the next few years. She is an epidemiologist (medical researcher) and is currently working on a doctorate at the UMass Medical Center in Worcester. She intends to devote her career to research in s.b. related issues and ultimately help to find ways for people with s.b. to live longer, happier, healthier lives.

Ginny spends her spare time involved in music and dance, performing with the Boston-based swing band The Mood Elevators and Morris dancing (a traditional English folk dance) with Muddy River Morris of Waltham. She hopes to encourage both her children to become involved in the arts, particularly music, which she believes can enhance the lives of people with physical limitations.



CORI COUTURE, MALDEN, MA (Board Member) is a 40 year-old adult with s.b. She lives in Malden with her husband Craig, her step-son James and their dog Willow. When not editing the MSBA's award-winning newsletter, she works as a freelance computer consultant. She works with private clients in their homes, helping them with a wide range of issues from bookkeeping to producing marketing materials to setting up email systems and troubleshooting system problems. On occasion, she does motivational speaking based on material she wrote for her Masters in Creative Arts in Learning from Lesley College. The topic of these presentations is how she used the arts to cope with growing up with spina bifida. She has an undergraduate degree in Theatre from Northwestern University, loves to sing and play board games.

Cori joined the Board of Directors 5 years ago and was instrumental in starting the MSBA's Youth and Adults Group and coordinating the MSBA's web site. She set up all of the MSBA's online discussion groups, and is constantly badgering new members (in the friendliest possible way) to join these groups. They are fantastic tools for communication and enrichment. Cori enthusiastically welcomes new members to the MSBA, and encourages everyone to ask questions (there are no stupid ones!). The MSBA exists so that we can share our knowledge and experience with each other.

JEN KUHAR, FRAMINGHAM, MA (Clerk, Board Member) has served on the MSBA Board for approximately four and a half years, and has held the Clerk position for three. An adult living with spina bifida (level L4-5, S1-2), she got involved to meet and help others affected by s.b. Shortly after joining the Board, she worked with other Board Members to help found the MSBAYA Group, which now has over 90 members. Jen believes that with self determination, independence is achievable for folks with s.b. and she stresses the importance of maintaining a "can do" attitude. In addition to her clerical duties within the organization, she serves on the MSBAYA Planning Committee, Holiday Party Committee, Finance Committee and Canister Committee. She was recently appointed to the SBAA Awards Sub-Committee for the 2006 Conference in Atlanta, Georgia.

Jen lives in Framingham, holds a Bachelor of Science in Accounting from Saint Michael's College in Vermont, and currently works for The TJX Companies in Framingham in its Finance Division. She has a younger brother Kevin, who, along with her parents, resides in Florida. Jen is an avid Red Sox fan, enjoys spending time with friends, loves traveling, attending Red Sox games and concerts, and spends most summer weekends at the ocean. Being a college hockey fan has brought her all over the country (New York to California), and you can be sure to find her at the TD Banknorth Garden during the NCAA Hockey East Tournament in March.

MATT NEAL, MARLBOROUGH, MA (Board Member) lives with his wife and fellow Board Member Ginny Briggs and their two children, Grace (age 5, s.b. level S1-S2) and Andrew (age 7) in Marlborough, MA. Matt joined the Board 2-1/2 years ago to meet other families affected by s.b. and to become more involved in the s.b. community. Matt is the manager of the MSBA's database, and has been working hard over the past year to hone the way we organize information, so that we might better serve our members. With an undergraduate degree in metallurgy and a Master's degree in Electronic Materials from MIT, Matt spent many years working as a scientist and engineer in the private sector. Then, two years ago, he decided to try his hand at teaching. He now works as a math teacher at Clinton High School in Clinton, MA and is enjoying his new career.

BRIAN PACKARD, NORTH ANDOVER, MA (President, Board Member) lives in North Andover with his wife, Cara, and their three children Katie (age 7), Daniel (age 5) and Kevin (age 2). Brian has served on the MSBA Board since 2000 and held the office of Vice President prior to his current role as President. Brian joined the Board after his daughter emerged from a long wave of s.b.-related medical crises and surgeries during her first two years of life. Then and now, Brian seeks to bring his passion and energy to the MSBA, focusing on developing the organization with new funds, programs and structure. He created Team MSBA, the marathon team that has raised nearly $250,000 for the MSBA in its three appearances in the Boston Marathon (he ran two of them himself). He also helped create the Parents Helping Parents Program, the first MSBA web site and led the creation of the MSBA's Strategic Plan. Brian works in Andover at Philips Medical Systems, where he is Business Director of a home defibrillator group. His "spare" time is spent playing with the kids, coaching/playing soccer and obsessing over his two sports loves -- the Notre Dame Fightin' Irish and the Boston Red Sox. Brian looks forward to continuing to help the MSBA grow into a stronger organization, with Cara (who runs the Benefits Program and the Parents Helping Parents Program) continuing her role as "behind-the-scenes-boss".

BRENDAN SULLIVAN, CHARLESTOWN, MA (Treasurer) is an adult with spina bifida who resides in Charlestown, Massachusetts. For the past four years Brendan has served the MSBA as a member of the Board of Directors and has held the office of Treasurer for the past three years. This December, Brendan will step down from his position on the Board, but will remain active in the MSBA through his duties as Treasurer. In his four years on the Board, Brendan has helped build the MSBAYA and has served on two National SBAA Committees. In 2004, Brendan was a member of Team MSBA, the Boston Marathon team that ran to garner financial support for the association, and finished his first ever marathon in 6 hours and 45 minutes.

An avid sports fan, Brendan fulfills his love for athletics daily as he is employed as an Assistant Athletic Director at Stonehill College in Easton, Massachusetts. As his role changes within the MSBA in the coming months, Brendan looks forward to continuing to help with the strategic financial policy of the association while witnessing the great work of the organization from the perspective of a member.

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

MSBA YOUTH & ADULTS GROUP

MSBAYA FOCUS

BY AIMEE SHANKS

Hello Everyone. Fall is upon us. Summer has faded — and a busy one it was for the MSBA Youth and Adults Group! Thirteen of us traveled to Minneapolis, MN for the Annual SBAA Conference in June, meeting and mingling with many from all over the world. What an awesome opportunity!

In late July, we gathered for the Annual MSBA Picnic and hads lots of fun! The MSBAYA Group also enjoyed a day of bowling on August 9, 2005 at Lanes and Games in Cambridge, MA. Whether it was a gutter ball or a spare, lots of laughs where heard throughout the alley.

On September 24, 2005, we tried our hand at a Sports Day at the Mass. Hospital School in Canton. We played softball and hockey. The day was facilitated by Nancy Bazanchuck, Program Coordinator of Children & Family Service's Adaptive Sports & Recreation Program. Nancy showed us how to play utilizing our individual abilities.

On November 6, 2005 the Group will meet at Children's Hospital Boston for an afternoon of Board Games from 1:30 to 4:30PM. On December 4, 2005, we hope to see you at the Annual MSBA Holiday Party at the Hampton Inn in Natick. Being held from 12:30 to 5:00 PM, this event will be a great opportunity to mix and mingle with MSBA kids and parents. On January 22, 2006, we are planning lunch at Uno's at the Burlington Mall. Then

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

Michele Scaramozza
Phone: 339-927-7227
Email: mozzas@comcast.net

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

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!

UPCOMING MSBAYA EVENTS

• Sunday, November 6, 2005	**Board Game Day** (1:30 pm - 4:30 pm)	Children's Hospital, Boston
• Sunday, December 4, 2005	MSBA Holiday Party (12:30 pm - 5:00 pm)	Hampton Inn, Natick
• Sunday, January 22, 2006	Lunch at Uno's (1:00 pm)	Uno's, Burlington Mall
• Thursday, March 9, 2006	Jazz Concert: Lisa Thorson	Wheelock Family Theatre, Boston

on March 9th, 2006, we are organizing an outing to see/hear Jazz Vocalist Lisa Thorson at the Wheelock Family Theatre.

As you can see, the rest of 2005 will be very active, and 2006 is already shaping up to another exciting year for the MSBAYA Group. If you'd like to get involved with choosing and organizing MSBAYA events, consider joining our Planning Committee. Just contact one of the current committee members (contact info in the box on the facing page).

Meanwhile, Please watch your mailboxes, MSBA newsletters and the MSBA web site (www.msbaweb.org) for the latest information regarding upcoming events. We hope to see you soon!

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 one of the Committee
members listed on the previous page.

ADULT HEALTH CARE GUIDES HAVE ARRIVED!

THE SBAA HAS PROVIDED THE MSBA WITH HEALTH CARE GUIDES FOR ADULTS WHO HAVE SPINA BIFIDA. WE HAVE A LIMITED NUMBER OF COPIES 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).

Bits and Pieces

…from web sites to single events to quick tips…

Please submit Bits and Pieces to Hyacinth Bellerose: bellerose33@charter.net .

By Hyacinth Bellerose

- **The National Center on Physical Activity and Disability (NCPAD)** is a web site with a myriad of resources to promote substantial health benefits that can be gained from participating in regular physical activity. The slogan of NCPAD **is *Exercise is for EVERY body***, and every person can gain some health benefit from being more physically active. This site provides information and resources that can enable people with disabilities to become as physically active as they choose to be. From summer camps to local programs organized by state and town, to upcoming events, it's worth checking out! www.ncpad.org
- **Pathways Awareness Foundation** is a national non-profit organization dedicated to raising awareness about the benefit of early detection and early therapy for children with physical movement differences. They have some interesting information on tracking development as well as a **growth chart** and **development chart**. www.pathwaysawareness.org
- **Mass Travel Journal and Boston Central web sites** Looking for something to do this weekend? Check out www.masstraveljournal.com and click on *Upcoming Events,* for a listing to meet every interest. Between this web site and www.bostoncentral.com, you can make each weekend a mini-vacation!
- **Student Independent Living Experience (SILE)** This UMASS program located at the Massachusetts Hospital School in Canton offers programs three times per year on independent livings skills at the following three levels: Introductory, Skills Builders, and Transitional. For more information, contact Bryan Drake at 508-856-7604 or bryan.drake@umassmed.edu.
- **Wheelchair Soccer** If you are interested in wheelchair soccer in the Springfield area, contact Nancy J. Bazanchuk, Program Director of Child & Family Services' Disability Resource Program, 367 Pine St, Springfield, MA 01105. Phone: 413-788-9695. Fax: 413-739-4599. Email: nbazanchuk@cfs.org. Web site: www.cfs.org.
- **The Massachusetts Hospital School** has a web site to provide support, share information, and build community for MHS families. However, the links and resources on the site are offered to and available to all of us. There are some great ideas and resources on the site. It's worth checking out when you have a chance! http://www.geocities.com/mhsfamilyoutreach/

QUICK SHOPPING IDEAS:

- **Dynamic Living** www.dynamic-living.com: Products (from the car to the kitchen) to make life easier
- **S&S Worldwide** http://www.ssww.com/store/browse/grp=HCR: Products for therapy, rehab and games
- **AliMed** http://www.ortho-rehabilitation-alimed.biz/p/fullpage.php?page=t1: Cool products (walkers with baskets!), orthopedic items, home health care and more. Check out the virtual catalog.
- **Beyond Play** Dolls in wheelchairs? Dolls with crutches? http://www.beyondplay.com/CATALOG/DRA1.HTM

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.*

Fundraiser to Benefit the MSBA

The Spina Bifida research fundraiser, being hosted by the Foti Family

—> —> —> **!! HAS BEEN RESCHEDULED !!** <— <— <—

The New Date is Saturday, November 12, 2005

Includes dinner, dancing, and cash bar, as well as raffles and door prizes.

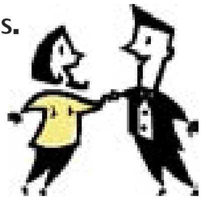
Proceeds to benefit Children's Hospital Boston and The MSBA.

Location: Danversport Yacht Club Time: 7:00pm

Cost: $55.00 per person

To order tickets, call Rosalie Foti at: 978-283-6447

NEW DATE!!



MSBA CALENDAR OF EVENTS

Date	Event	Location
November 6, 2005	**MSBAYA Board Game Day** (1:30 pm - 4:30 pm)	Pavillion Conference Dining Rm., Children's Hospital, Boston
November 7, 2005	MSBA Board Meeting (**Annual Meeting**) (7:00 pm)	The Centres at Burlington
November 12, 2005	**Foti Family Dinner/Dance S.B. Benefit** (7:00 pm) **** PLEASE NOTE **NEW** DATE! ****	Danversport Yacht Club, Danvers, MA
December 4, 2005	**MSBA Holiday Party** (12:30 pm - 5:00 pm)	Hampton Inn, Natick, MA
December 5, 2005	MSBA Board Meeting (7:00 pm)	Lahey Clinic, Burlington, MA
January 9, 2006	MSBA Board Meeting (7:00 pm)	Lahey Clinic, Burlington, MA
January 22, 2006	**MSBAYA Lunch @ Uno's** (1:00 pm)	Uno Restaurant, Burlington Mall
February 6, 2006	MSBA Board Meeting (7:00 pm)	Lahey Clinic, Burlington, MA
March 6, 2006	MSBA Board Meeting (7:00 pm)	Lahey Clinic, Burlington, MA
March 9, 2006	**MSBAYA Jazz Concert: Lisa Thorson**	Wheelock Family Theatre, Boston

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 .

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.

Catheters For Sale

A member of the MSBAParents Yahoo!Group has catheters for sale.

Details: They are Mentor self cath 6" sterile female catheters; 14FR, straight tip. They're latex free.

Price: $23.00 per box of 31.

She has 61 boxes, but will sell the whole lot at a 10% discount.

Interested? Contact: Denise (Drhon@aol.com)

MSBA Volunteer Opportunities

To find out more about new committees the MSBA is forming and how they fit into the larger picture of our organization as a whole, have a look at our Strategic Plan, now available on our web site (www.msbaweb.org). From there, you can also use online forms to sign up for any of the new committees.

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

MASSACHUSETTS SPINA BIFIDA ASSOCIATION

733 Turnpike Street, #282
North Andover, MA 01845

Phone: 888-479-1900

Web Site: www.msbaweb.org

WINTER NEWSLETTER DEADLINE

JANUARY 6, 2006

PLEASE SUBMIT ARTICLES AND INFORMATION FOR PUBLICATION TO:

Cori Couture
c/o MSBA
733 Turnpike Street #282
North Andover, MA 01845
Email: coricouture@gmail.com

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.