MSBA News

A Publication of the
Massachusetts Spina Bifida Association

Member, Spina Bifida Association of America

- Fall 2004 -

Don't Miss
the MSBA Holiday Party!

Saturday, December 4, 2004

from 1 - 5 pm

at

Boston College

(see AND SAVE! Page 3 for details)

Inside this Issue

MSBA Membership & Benefits

Letter from the President

By Brian Packard

Hi everyone. I hope you and your families are enjoying this autumn season and, more importantly, baseball's Fall Classic. As I write this, the Red Sox have won an exciting Game One of the World Series and look confident heading into Game Two. Superstitious New Englander that I have become, I dare not make any projections. Like the rest of Red Sox Nation, our family will be locked to the TV for the rest of this week, and hopefully by the time you read this, we'll all be basking in the glow of a broken curse.

Since the last newsletter, the MSBA membership has not gotten together for any major events. However, our MSBA Youth and Adults Group did meet for an afternoon of fun and sharing in mid-September. They gathered at Boston Beer works near North Station to watch a Patriots Game. About 20 people attended and a great time was had by all. The MSBAYA Committee also met to plan events for the next 6 months and to outline goals and resources for the group.

We hope that our Parent's Support Group will begin to take root and grow like the MSBAYA has. If you are a parent of a child with spina bifida and would like to share your thoughts, concerns, or ideas or you would just like a group of people to talk to about raising a child with spina bifida, please contact Hyacinth Bellerose or Cara Packard (contact info on page 2).

Hopefully some of you had a chance to meet with Cori Couture at this month's Children's Hospital myelodysplasia clinic. Cori was manning a new MSBA informational table for us. Going forward, we will be periodically staffing this table in the waiting area to educate the s.b. community about MSBA's services, as well as to recruit new members. And, there's free food, so stop by the next time you have a clinic appointment!

On the organizational front, your MSBA Board continues to work hard on long-term strategy and governance issues. As follow-up to our all-day work session in August, the Board continues to formalize our strategic plan and organizational structure during regular meetings. At the October Board Meeting, we reviewed our By-Laws, which had not been revisited in several years. We

Continued on Page 7

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25 Devon Court, North Andover MA 01845
Email: Muna000@aol.com

M.S.B.A TELEPHONE	**888-479-1900**
M.S.B.A. FAX	**978-549-8725**
S.B.A.A. TELEPHONE	800-621-3141

COMMITTEE CHAIRPERSONS

ARNOLD CHIARI INFORMATION
Kevin & Maureen Walsh 781-337-2368
67 Spring Street, Weymouth MA 02188
Also try World Arnold Chiari Malformation Association at http://www.pressenter.com/~wacma/

BENEFITS PROGRAM (Formerly "Camperships")
Cara Packard 978-683-6644
178 Hay Meadow Road, North Andover MA 01845
Email: packard44@comcast.net

Joanne Mahoney 781-894-2749
98 Hibiscus Avenue, Waltham MA 02154

CANISTER COLLECTIONS - VOLUNTEER NEEDED

EDUCATION / SCHOLARSHIPS
Kevin Kelly 781-659-2315
35 Harbor Lane, Norwell MA 02061

FUNDRAISING
Hyacinth Bellerose 978-549-4848
33 Forest Street, Dunstable MA 01827
Email: bellerose33@charter.net

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

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

MEMBERSHIP
Matt Neal 508-460-7647
Email: mattneal@alum.mit.edu

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96 Pine Hill Road, Ashland MA 01721
Email: meshorey@attbi.com

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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

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

MARK YOUR CALENDARS FOR THE 2004 MSBA HOLIDAY PARTY!

SATURDAY, DECEMBER 4, 2004 FROM 1:00 PM- 5:00 PM AT BOSTON COLLEGE (NEWTON CAMPUS THIS TIME, NOT CHESTNUT HILL!)

DIRECTIONS ON BACK OF THIS PAGE.
PLEASE CUT OUT THE WHOLE PAGE, AND BRING IT WITH YOU.

PARTY WILL INCLUDE:

- Lunch
- Prizes and Entertainment for all ages.
- Special Holiday Guests!!
- Music
- Coloring contest for kids (see below)
- Yankee Swap for adults*(bring a gift worth no more than $10) *Adults with s.b. do not need to bring a Yankee Swap item.

****** PLEASE RSVP BY NOVEMBER 26, 2004 ******
(INCLUDE NAMES & AGES OF CHILDREN ATTENDING!)
BY PHONE (888-479-1900) OR ONLINE AT < WWW.MSBAWEB.ORG >.

Special thanks to:
- *Boston College for their hospitality*
- *Jen Fitz-Roy and the rest of the Boston College Disability Council for all their help with organizing this event.*

KIDS - BREAK OUT THE CRAYONS AND START COLORING! YOU COULD WIN A PRIZE AT THE MSBA HOLIDAY PARTY!

(SEE PAGES 5 & 6 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 Stuart House
885 Centre Street
Newton, MA
(on the Newton (Law School) Campus of Boston College)

TIME:
1:00 pm - 5:00 pm

DIRECTIONS

FROM THE SOUTH AND SOUTHEAST:

- Take Routes 95 or 24 north to Route 128/95 north.
- Take Exit 24 (Newton, Route 30/Commonwealth Avenue).
- * Follow Route 30 (Commonwealth Avenue) east for approximately 4 miles (past the main campus of Boston College) to the traffic light at the intersection of Commonwealth Avenue and Centre Street.
- Turn right onto Centre Street.
- The Law School campus entrance is 1/2 mile ahead, on the left.

FROM THE NORTH AND NORTHEAST:

- Take Routes 3, 93, or 95 south to Route 128/95 south.
- Take Exit 24 (Newton, Route 30/Commonwealth Avenue).
- To continue, see directions from the South and Southeast above.*

For a printable map, please visit: http://www.bc.edu/about/maps/ then click on the link to the PDF file for the Newton campus.

FROM THE WEST:

- Take the Massachusetts Turnpike (Route 90) east to Exit 17.
- At the end of the ramp, turn right at the first traffic light, onto Centre Street.
- The Law School campus entrance is approximately 1 mile ahead on the right.

FROM THE MAIN (CHESTNUT HILL) CAMPUS OF BOSTON COLLEGE:

- Continue west on Route 30 (Commonwealth Avenue) for approximately 2 miles, to the traffic light at the intersection of Commonwealth Avenue and Centre Street.
- Turn right onto Centre Street.
- The Law School campus entrance is 1/2 mile ahead, on the left.

FROM BOSTON:

- Take the Massachusetts Turnpike (Route 90) west to Exit 17 (Newton).
- Continue straight at the end of the exit ramp; the Sheraton Newton hotel will be on your left.
- Immediately after the Sheraton Newton, turn left; this will bring you around the hotel and over the Mass Pike.
- Take the first right onto Centre Street.
- The Law School campus entrance is approximately 1 mile ahead on the right.

TO GET TO THE STUART HOUSE ONCE YOU ENTER THE CAMPUS:

- Take the first left.
- You'll drive between the Law Library on your right and a bus stop on your left into the parking lot for the Stuart House and its attached buildings.
- The accessible entrance to the Stuart House will be on your right as you enter the parking lot.

2004 COLORING CONTEST

Coloring Contest!

Hey, Kids, color the picture on the other side of this page, then send it to us, and you could win a great prize at our Holiday Party!

Name: ______________________
Age: ______
Address: ______________________
____
____

Mail Your Entry to:

Massachusetts Spina Bifida Association
2004 Coloring Contest
733 Turnpike Street, #282
North Andover, MA 01845

President's Letter — Continued from page 1

have also recently created and approved advertising policies and a rate card for this newsletter and re-drafted our Benefits Program language to best convey the spirit of this MSBA funding source.

Speaking of the Benefits Program, we have some exciting news. This year we will again provide $500 toward SBAA Conference expenses (over and above the normal $500 Annual Benefit). And, for members willing to provide a minor service, such as writing a newsletter article or organizing an event, we will authorize an additional $250. That's a total of $1,250 for Qualified Members!

Lastly, check page 3 for details on this year's Holiday Party, to be held at Boston College's Newton Campus. We hope to see you there.

Best health and happiness to each of you this Fall.

Go Sox! Brian Packard

SBAA CONFERENCE 2005

START PLANNING NOW…

BY HYACINTH BELLEROSE

The MSBA showed our true spirit with an incredible turnout at the Spina Bifida Association of America's annual conference in Washington D.C. this past June. Ask anyone who attended if it was worth his/her time and money and I am sure you will receive a resounding yes! The information provided during conference sessions and the opportunity to meet peers on a daily basis is not describable; you just have to attend. The location just outside of Washington D.C. was not exciting but, I spent a few hours online researching this coming summer's location, it looks like it will provide a lot of fun and accessibility.

The 2005 SBAA Conference will be held June 26-29, 2005 in Minneapolis, Minnesota (near where Mary Tyler Moore threw her hat up into the air!). Minneapolis is the home of Target, Marshall Fields, many museums, a wide variety of restaurants, and the Minnesota Twins. It is also the home of the Mall of America, which includes LegoLand, the Snoopy Roller Coaster, hundreds of stores, as well as restaurants and even nightclubs. In other words, Minneapolis offers more than enough to keep you enthralled for as long as you can stay.

GENERAL INFORMATION

The Conference host hotel is the Hyatt Regency and the overflow hotel is the Millennium Minnesota. These hotels are located in the 1300 block of the Nicollette Mall; a pedestrian street downtown, and are connected to each other via walkways. The cost of a standard room is $125.00 per night plus taxes and fees. At this time, airfares appear to be about $300-$400 round trip and most flights are nonstop. The next edition of the newsletter will contain more detailed information about the two hotels, as well as about airlines and ground transportation. In the meantime, check out the latest MSBA Benefits Information and Application, on pages 12 & 13, to find out how you can obtain up to $1250.00 toward attending the Conference.

ACCESSIBILITY

The best news about this year's conference is that Minneapolis is a very accessible city. The new "Light Rail" and all city buses are fully accessible. This means you can get to the Warehouse District, Mississippi River parks, and the Mall of America easily, independently and inexpensively from the two conference hotels.

Prior to going to Minnesota, I suggest checking out < www.accessminnesota.org > for hints and useful information. he site offers details on parking, bathrooms and accessible entrances to places all over the city. Specific information (such as exactly where a restroom is located in any given building — with detailed in-building directions) is available for listed restaurants, attractions, etc... As we get closer to Conference, the MSBA will be putting together a package of the information we find about places near the Conference Hotels, about transportation and anything else that seems fun or useful. If you find any material or web sites of particular interest, please send them to me (Hyacinth Bellerose, contact info inside front cover) by postal mail or email, so that I can include them in this Conference Information Package.**

ADDITIONAL INFORMATION

The web site for information and links about Minneapolis in general is < www.minneapolis.org >. It is a truly wonderful and interactive website. Those of you more technical that I can even download information and a personalized guide onto your PDA. You can order a free visitors' guide from this site or by calling the Minneapolis Convention and Visitors Association at 1-888-676-6757.

***If the MSBA has a large group of people attending conference again this year, the MSBA will host a meeting in early June to hand out the MSBA's Conference Information Package and to discuss meeting places at Conference.

Watch for further details in the next newsletter.

MY STORY

BY JESUS ARROYO, COLORADO SBA

"Hi! My name is Jesus Arroyo. I'm 28 years old. I'm married. I have a dog and 2 fish. I like to read. I like to go down to the 16th St. Mall in LoDo and people-watch. I hope to go back to college someday."

That's how I introduce myself now. It wasn't always like that. I used to say, "Hi. My name is Jesus and I was born with Spina Bifida." Maybe I would add, "I was born in El Paso, Texas but my family moved to Denver when I was 3 months old, in order to find better medical care." I used to say that because, in my head, that's all I was....a disability. But that said nothing about my interests, about my likes and dislikes, nothing about my hopes and dreams. I've learned a lot in the past year, and while this story may seem like one of pessimism and sadness, if you read to the end you will see it's a story of hope and happiness. And hopefully it's a story that will inspire.

Growing up, while I did have friends, it was often a struggle to get to know people. And even with the friends I had, I never really got out socially and did much with them. I was fortunate in not needing any shunt surgeries until I was 15. Then from 15 to the age of 20, I had atleast one surgery a year. This contributed to the depression I've had most of my life. I know there are many people out there who say, "Just one a year?! That's nothing!" But to me it was new and scary and sad. I was hardly in high school, hardly saw my friends. In college, I had to drop out because of more surgeries, as well as dealing with this growing depression.


The author, Jesus Arroyo and his wife Marie.

I'd always experienced what I later learned were classic symptoms of panic attacks. In situations that I was not comfortable with, which were most of them, I would start to sweat... my chest would get tight and start to hurt... my heart would beat faster and faster. I felt as if the whole world was watching me and laughing at me. I was afraid of meeting new people, of being in new social situations, afraid of getting stared at, laughed at, pointed at. As a teenager I even grew my hair down to my waist and had piercings on my face. But this wasn't any sort of "rebellion" thing. It was my way of getting people to stare at something other than what I thought were my glaring physical disabilities.

Depression. I had it. Big time. All the surgeries and all the medical issues only made it worse. My home life didn't help much either. My dad was not a very nice man. I've struggled with what to say about him in this story. He is such a big part of my pain and my depression, but at the same time it's still personal and shouldn't be described in detail. I'll just say that while there was no physical abuse whatsoever, there was verbal and emotional abuse every day. He said things; he screamed things at me that you should never say to your child, let alone your child born with disabilities. And I believed him. Growing up, your parents, especially your father, might as well be God. You hang on his every word. And when those words are negative and hurtful, poor self-esteem becomes the least of your sad issues. I don't blame my mom. She was amazing. She continues to be amazing. She was always there for everything. She was supportive and caring and loving and she is truly the only one who never left in my life. I have been blessed to find my wife, Marie, who is also amazing, but growing up, my mom was all the love and support I had. I don't blame my mom because I am adult enough now to know that life is complicated. It's not as easy as "Your husband is mean. Leave him." She was 23 years old. She was a housewife. She didn't speak the language of this country. She didn't know anybody. She also had my brother to take care of. If she left my dad, where was she going to go?

So I did the only thing I knew how to do. Stay in my room. Literally. If I came out, my dad would yell at me about something. I spent a lot of time in there. Alone. Sad. Scared.

All of this started to change in August of 2002. My wife and I had been in our own home for a year. But I seemed to be getting more and more depressed. I'd cry a lot. I'd feel hopeless and often scared, but never knew why. That's when I decided (and it was not easy) to finally get the therapy that everybody always knew I needed, but that I never admitted to myself. I spent 8 months with a therapist. While I did learn a few things and did improve somewhat, it didn't help too much. It helped me stabilize enough that I didn't want to die, but not enough to really be happy. She had recently gotten her Master's degree, was working towards her license, and had been working exclusively with rape victims and schizophrenics before I showed up. Obviously heavy-duty stuff, but stuff that really didn't prepare her to deal with a disabled man who was dealing with depression.

In February 2003 I decided to discontinue therapy with her. I had gotten myself well enough that I thought about going to the National Spina Bifida conference in San Antonio that June. In the past it was something I would NEVER have done. I never participated in any of that — Not CSBA [Colorado SBA], not the Adult group, and certainly not a national conference. I always thought, "Why bother? Nothing will change. I'll still be me. I'll still have SB. I'll still have problems and nobody will change that. How is hooking up with a bunch of people in SBA going to help anything?" Still, I decided to give the national conference a try.

WOW! WAS I AMAZED!

Before the conference I had never even seen another adult with Spina Bifida. I knew they were out there but I never saw or met one. I was always so isolated and alone. And when I went to the Spinal Defects clinic every year for check ups, it would be at Children's Hospital. I didn't know any adults living with SB. But when I got to the conference, I saw and met so many people. Some were in chairs, some ambulatory (like me), and even some professionals. I met a doctor there with SB! He was a presenter at some of the seminars. I finally met the president of our local Chapter, Tom Baroch. It was all so exciting!

I attended one seminar in particular that changed my life. The class was on NLD's (non-verbal learning disabilites). The doctor with SB, Tim Brei, was presenting it. He began by saying that not everyone with SB has all these issues but most people with SB have some of them. He started listing: We aren't so good at math. We have trouble with too much visual information. We tend to write everything down. We make lots of lists. We are very verbal and great spellers. We have trouble processing too many visual cues at once. He said all these things that everyone in the room was giggling at, because we could all relate. And I giggled too. But at the same time, I felt, for the first time in my 27 years of life, less alone. I felt like I belonged. I thought to myself, "It's not just me. I'm not stupid. I'm not a freak." And I felt vindicated. Every time my father would call me names for not being able to follow a simple set of verbal instructions, he was not only wrong morally, but wrong scientifically. NLD's cause us to forget half the list before we even start because of the fact that people with NLD's tend to think in words and not pictures. But the human mind works just the opposite and can hold more pictures than words, so we end up forgetting half the list. Every time my dad called me names as a child for not being able to find the hammer in our garage, it wasn't my fault. I never found the hammer because the moment I walked into the garage, I was overloaded with too much visual information. I never knew where to start looking.

That one class started to change everything. I began to understand more about myself; why I was so good at English, so bad at math. Why I could just talk and talk (as evidenced by this story) and was so bad at finding the car in the middle of a huge parking lot (too much visual stimuli). Why I can't read maps or blueprints to save my life but I spent my time in elementary school ordering 500 page "Mysteries of the Unknown Universe" books from Time-Life instead of reading the latest adventure by Judy Blume. I finally felt "normal". I finally felt peaceful. I finally felt like I "belonged" somewhere. I finally felt.........Home.

After that conference, I came back, called up Tom Baroch and Marge Hays and all the other wonderful people in the CSBA Adult group and asked if I could join. I wanted more of that feeling. I wanted more of that happiness and friendship and feeling like I was part of a group. I also really applied myself and tried to find another therapist. With the help of a wonderful and amazing PCP I had, and the psychologist who worked with him (but didn't accept Medicaid in her private practice unfortunately) I found a wonderful psychologist. She has a PhD. She's been doing this a long time and has dealt with many people suffering from depression. It's been amazing. She helps me see things in a different light. She helps me realize things I never knew were there. She doesn't change my way of thinking for me. But she helps me do it myself. We go back and try to figure out why I am the way I am. We try to go back to the foundation of my life and my way of thinking and try to change it. It's great! And the CSBA Adult group has been so good for me. I look forward to our monthly meetings. I enjoy that feeling of belonging. Both those things, therapy and CSBA, has helped in other ways. I get out more. I do more things. I am active. I don't notice if other people are staring. I don't care anymore. I just want to live life. I finally realized that mental health is a very real issue. It's real and it's not that you're "crazy".

It's not that you just need to "snap out of it". There are very real things going on in your brain, with seratonin levels and other brain chemicals. "Depression" doesn't equal "crazy". And therapy helps change all that.

So is life perfect these days? Did my SB suddenly and magically go away? Do I have all the answers? Is life pain free now? The answer to all those is NO. Life still has its ups and downs. I still have bad days. And every once in a while, I wake up sad and think, "What's the point? It's all pointless anyway" and go back to bed. But those days are fewer and farther between. I have a lot more good days than bad days. I am more optimistic about my life and my future. I make plans. I never used to make future plans. I just always figured I'd die young. But meeting people in their 70's with SB who are still active, even in chairs, and optimistic and happy, inspires me.

So no, I don't have it all figured out. But I believe. **And I've stopped asking "Why me?" and now I just think, "Who knows why me. I believe in a god and I'll ask Him when I get there. In the meantime, I am going to live."** And if I can get one more person to experience a little more joy in their life... if I can get one more person to maybe learn a little bit more about NLD's and think "Hey that's me. He's describing me. Maybe I'm not alone"... if I can get one more person to join a local SB Association, and specifically to join an Adults Group... I did good. If I can get them to join, and feel the friendship, the camaraderie, the happiness that I feel in being part of the group, I will have done what I set out to do.

P.S.: For those who want to know... My mom went back to college at 35. She has a Masters in Education, is now a teacher, has plenty of friends, is happy and is doing just fine.

This article originally appeared in the Colorado Spina Bifida Association's newsletter, The Insider, and appears with the Author's kind permission.

If you would like to contact Jesus, you can email him at: ***Aguito@aol.com***. He is a fantastically nice guy!

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, 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.
- In order to receive the MSBA's quarterly newsletter, the SBAA's newsletter *Insights*, and to receive other MSBA benefits, it is necessary to be a 'Qualified Member" of the Association.
- There is no membership fee, but tax deductible donations are appreciated. ***To become a member, simply 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 Member"?** A person with Spina Bifida who 1) resides in Massachusetts or a New England state that does not have its own SBAA affiliated entity, and 2) who is actively registered with the MSBA. (See Benefits information on page 12 for more details.)
- Please send us an update whenever there are any changes to your information.
- Members can also update their information by sending an email to mattneal@alum.mit.edu.

MSBA EMAIL REQUEST

The MSBA is working on getting information to you more efficiently. If you are interested in being on an email list for reminders about upcoming events, or one for parents or teens, please send your email address to Matt Neal at mattneal@alum.mit.edu . Please mention which list you'd like to join.

To join the MSBA Youth and Adults Group online (for folks with s.b. ages 17 and up), please visit:

< http://groups.yahoo.com/group/MSBAYA >.

MSBA MEMBERSHIP APPLICATION/UPDATE FORM

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

Type of Membership:

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

Name of person with spina bifida: ______________________
Date of Birth ♦ (Important. This information 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 sb lesion, suggestions, etc...):
____
____
____
____
____

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

** MSBA Benefits Programs **

Qualified Members of the MSBA are now eligible for up to $1250.00 a year through our Benefits Program and the 2005 Special Conference Benefits Program!

What is a "Qualified Member"?

A person with Spina Bifida who 1) resides in Massachusetts or a New England state that does not have its own SBAA affiliated entity, and 2) who is actively registered with the MSBA. 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 Member is entitled to $500.00 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 to the MSBA by the Qualified Member or their parent or guardian via postal mail or email, and 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 Member to receive Benefits funds:

1. Reimbursement: The Qualified Member 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 Member 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.

2005 Special Conference Provisions

This year, Qualified Members are entitled to a **Conference Benefit of $500.00** (in addition to the Regular Annual Benefits Program), to be used expressly **for expenses related to attending the SBAA Annual Conference** in Minneapolis, MN., June 26-29, 2005. **A** further **Bonus Benefit of $250.00** will be granted if the member agrees to perform a service for the MSBA, such as serving on a committee, writing an article for the newsletter about Conference experiences or helping to organize an MSBA event.

The terms for approval and payment are the same as for the regular Annual Benefits Program. *Please note*, however, that the MSBA must receive the application for the 2005 Special Conference and Bonus Benefits *in advance* - even if the amount is only an estimate of expenses to be finalized later.

Requests outside of this scope will be reviewed on an individual basis.
The MSBA reserves the right to revise this policy in accordance with changing financial position of the MSBA.

MSBA BENEFITS FORM

Name: ____________________

Street Address: ____

City, State, Zip: ____

Telephone: __________________ **Email**: ______________________________

I AM APPLYING FOR:

___ **MSBA Annual Benefit of $500**
 ___ Receipt Attached
 ___ Make check payable to enclosed provider

___ **2005 Special Conference Benefit of $500**
 ___ (estimate) OR ___ (final)
 ___ Receipt Attached OR
 ___ Make check payable to enclosed provider

___ **2005 Bonus Conference Benefit of $250**
 ___ (estimate) OR ___ (final)
 ___ Receipt Attached OR
 ___ Make check payable to enclosed provider

____
\+ ___________
\+ ___________
= ___________ GRAND TOTAL REQUESTED

Please attach an explanation of the benefit you are requesting and what it will be used for. No particular format is required.

Please tear out this application form and return it to:
MSBA Membership
733 Turnpike Street #282
North Andover, MA 01845

MSBA 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 9:30 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 any Board Member (contact info on page 2).

- **Strategic Planning:** The MSBA Board of Directors has been very busy since the last newsletter. Our all day Strategic Planning Session, held on August 22, 2004, was quite productive. During this meeting and the two subsequent Board meetings, we have made great progress in defining the short-term goals of the MSBA. (In this case, short-term goals are those we intend to accomplish in 2005.) We have also been solidifying a formal committee structure, which will help us to more efficiently engage you —the general membership — in the operation of the MSBA, by asking you to serve on some of these committees. In other words, to meet our 2005 goals, *we will need your help!* PLEASE contact us to find out how you can get involved in making the MSBA even better!
- **New Location for Board Meetings:** Starting in November, our monthly Board Meetings will be held in a new location — the Centres at Burlington.
- **Dominique Savinelli Leaves Board:** Effective August 23, 2004, Dominique Savinelli resigned from the Board, so she could fully focus on her studies. She began Law School at Boston University in August and seems to be doing well. We want to thank Dominique for all of her hard work while serving on the MSBA Board and wish her the best of luck. She will be missed by all, but we hope to see her periodically at MSBA events.
- **New MSBAYA Committee Members:** We are pleased to announce that MSBA members Aimee Shanks, Brandon Shanks, and Michele Scaramozza recently joined the MSBA's Youth and Adults Group Planning Committee. We are thrilled to have them aboard and are excited about the wonderful ideas and enthusiasm they all bring to the group!
- **MSBAYA Events Update:** The MSBAYA plans to get together about every 6 weeks going forward. In addition, we are making an effort to move our events around the state to better serve *all* of our membership. With this in mind, our next event will take place on November 7, 2004 — at Chili's Bar and Grill in West Springfield. We hope to see many new faces. Don't be shy. Get involved!! *(For more details on Youth and Adults Group Events, see the MSBAYA*

Continued on Page 19

WHO'S OUT THERE?

(MSBA MEMBER SPOTLIGHT)

THIS MONTH: WHY "WHO'S OUT THERE?" IS HERE

BY MATT NEAL

We're all over the place, and in a way we're all in the same place. The MSBA membership is currently 234 strong. We have members in 143 different towns and cities in Massachusetts, as well as 1 in Rhode Island, 2 in Connecticut, 3 in New Hampshire, 1 in Vermont, and 4 in Maine. — All over the place.

We're all in the same place in that we all are dealing with spina bifida; something that's very familiar to us and very strange to most everyone else. That's why we're in the MSBA and that's why we should be more familiar with one another. That kind of familiarity is not easy to achieve, since we're spread out the way we are. But one way to pretty easily find connections is to read about each other in the newsletter. And that is why we have this "Who's Out There" column; to let all of us know who else is out there.

You've already met three of your fellow members through this column, Diane Ramsey of Natick, Allen Johnson of Worcester, and Deihlia Nye of Franklin (back issues of the newsletter are on the web at < http://www.msbaweb.org >). At this rate it would take about 60 years to include a feature about each member, so obviously, that's not our goal. Nor are we trying, necessarily, to inspire with stories of great courage and accomplishment. The idea is really to get comfortable with the notion that we are real people that are a lot alike, that we share some common experiences and that, collectively, there is a wealth of experience out there on a diverse range of topics. The idea is to help make us all a little more approachable, to make communication between members a little bit easier.

Who do we pick to go into the column, and why? Eventually, we'd like to have featured a broad cross-section of the MSBA - people of all ages (and their parents), from all of the different regions we serve, coming from many different backgrounds. In other words, people who are different in some way from the people we've already featured - which means everybody and anybody. In fact, we would love to get input on future content. If you want to suggest someone for the column, or volunteer yourself, or even write a guest column, please let us know. Any comments about past columns or suggestions for improvement are also welcome, of course. You can send email to me at mattneal@alum.mit.edu or send a letter to Massachusetts Spina Bifida Association, 733 Turnpike Street, #282, North Andover, MA 01845.

This column is about you and for you. You are *who's out there*.

MSBA YOUTH AND ADULTS GROUP (MSBAYA) FOCUS

BY MICHELE SCARAMOZZA

Hello, everyone! For those of you that don't know me, my name is Michele. I am 28 years old. I have been a member of the MSBA for as long as I can remember and of the MSBAYA Group for almost a year now.

Growing up, I was involved in many different organizations for youth with disabilities, but as I got older and graduated high school, it was harder to find young adults groups to be involved in. So, I kept myself busy doing other things. I took college courses, worked many summers as a camp counselor, and eventually began working as a Transition Specialist, teaching independent living skills. Later, I took a job teaching youth with disabilities how to be leaders in their communities.

Unfortunately, in the last year, due to some issues I am having with my hands and arms, I to leave my job and go on disability. I will be having surgery soon to help correct it, and hopefully, will be back to work again before long. I can't wait!

Meanwhile, these difficulties bring me to why I joined the MSBA Youth and Adults Group. Throughout this period in my life things have been stressful. Leaving work was very hard, I moved out of my parents' house, and I've had to make a number of other big changes in my life. With the support of my family, I am working through it. However, I started to realize I needed more than just my family's help. I needed other young adults with spina bifida in my life that might be having or might have had similar issues to mine. This is when I decided to call the MSBA and see if there was anyone out there that could help me out. They told me about the MSBAYA Group, and suggested that I attend an upcoming event. I have been to several events since then, and have to say that I am hooked! Recently, I joined the Planning Committee for the MSBAYA Group, and am excited to tell you about some of our recent and upcoming activities.

In September, the MSBAYA Group got together to cheer on the Patriots at Boston Beer Works. What a blast it was! Although (if I may speak for most of us) I can't say we did very much cheering. We were having so much fun talking and laughing that some of us forgot there was a game to watch. (I was one of the guilty ones.)

I have to say this was the most fun I have had at an event yet. About 20 people attended. I knew some and enjoyed getting to know the rest. We spent the afternoon eating all kinds of great foods, playing pool, sharing resources (i.e.: Where did you get your cool wheels?!), and telling funny stories (i.e.: Where is the most bizarre place you've left a crutch or two – or even your wheelchair?).

This day really helped old friendships grow and new ones to begin. I can't wait to see everyone again and to meet more new friends and share laughs. I'll see you all in West Springfield on November 7th!


MSBAYA Planning Committee member Michele Scaramozza (left) with Patricia DeMoranville, MSBAYA Member and Co-Regional Represenatative for the MSBA in Southeastern MA.


Members get a chance to share stories and laughs at the MSBAYA's gathering at Boston Beerworks on September 19th. Pictured here: Michele Scaramozza, Lindsay Meuse, Karen Whittey, Ashley Whittey, and Patricia DeMoranville.

MSBA YOUTH & ADULTS GROUP COMMITTEE

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UPCOMING MSBAYA EVENTS

- **JANUARY 8, 2005: "LUNCH & LEARN" DAY, STURBRIDGE, MA. WE'LL HAVE SEVERAL SPEAKERS ON RELEVANT TOPICS AS WELL AS OPPORTUNITIES TO SHARE YOUR OWN STORIES. LUNCH WILL BE SERVED.**
- **FEBRUARY 19, 2005: DETAILS TO BE DETERMINED.**

For more information, visit the Youth & Adults Area of the MSBA web site < www.msbaweb.org > and watch your mailbox. Event flyers will be sent to all members 17 years old and up. If you fall into this age group, but have not been receiving flyers, we may not have your birth date entered into our database. To get it added, please contact Matt Neal (contact inside front cover) and ask him to add it for you.

MEDICAL RESEARCH CORNER

BY GINNY BRIGGS

FETAL SURGERY: A REPORT ON RESULTS SO FAR

Some of us are aware that surgery is available to treat babies with spina bifida (SB) before they are born. The approach was developed to potentially reduce the need for a shunt following birth by closing the spinal lesion in utero. Closure of the opening on the spine would stop leakage of cerebral spinal fluid (CSF) before the baby is born, reducing the severity or perhaps eliminating the progress of the Chiari Malformation. The absence of the Chiari may likely prevent the development of hydrocephalus as CSF can circulate freely. The need for a shunt following birth may then be eliminated.

The popularity of pre-natal surgery has been gaining momentum in the United States at several hospitals, including Children's Hospital of Philadelphia (CHOPS), Vanderbilt University Medical Center in Nashville, Tennessee, University of North Carolina at Chapel Hill and the University of California in San Francisco. The surgery has had significant success, with fewer children born with SB needing shunt placement. As we all know, life without a shunt would make things a lot easier for many people with SB. The procedure is not without risks, though. Surgery must take place soon after the SB is discovered, usually 22-25 weeks gestation. During the procedure, the fetus is actually lifted out of the womb for surgery, then placed back for the remainder of the pregnancy. Mothers must be followed closely until delivery, which may likely be premature due to trauma to the uterus. The procedure is risky to both mother and child. It is a very difficult decision to make, but the results have been promising. A recent paper was published in the American Journal of Obstetrics and Gynecology. It reports the outcome of 116 fetuses that underwent the surgery to repair spinal lesions. The authors report a decrease in the need for shunt placement in the first year of life following prenatal surgery.

Spinal lesion level	Number	Needed a shunt	Did not need a shunt
S1	16	10	6
L5	24	17	7
L4	28	16	12
L3	26	6	20
L2	14	4	10
L1	3	0	3
T12	2	0	2
T11	1	0	1
T10	2	0	2

Table 1: Comparison between shunt rates according to the level of the spinal lesion.

The best results were found in infants who:

1. had spinal lesions at L-4 or below
2. had surgery at ≤ 25 weeks gestation
3. had ventricle sizes of < 14 mm at the time of surgery (a ventricle is a hollow space in the brain)

The need for a shunt was broken down further into groups according to the level of the spinal lesion.

Table 1 summarizes the results:

The degree or severity of the Chiari Malformations in these fetuses also had impact on the need for a shunt (some fetuses had already begun to develop a Chiari before surgery). Other factors were considered in the study such as age of the mother and ethnic group, but neither had an effect on the need for a shunt.

It is important to note that the average delivery occurred at 33-34 weeks gestation and all babies were delivered by cesarean section. As premature birth can introduce further complications in an infant, the parents involved in this study were counseled about this and other potential risks (and benefits) of the procedure. Since the surgery has shown significant success in this and other studies, research continues to find ways of reducing the need for a shunt in people with spina bifida.

AUTHOR'S NOTE: I was 20 weeks pregnant when I considered prenatal surgery four years ago. They had performed nearly 100 procedures at Philadelphia Children's Hospital at the time and I would have satisfied their criteria for candidacy (less than 24 weeks pregnant, low level lesion of S1). However, my husband and I decided the risks outweighed the benefits in our case and agreed to proceed without surgery. We were told I would be required to stay in Philadelphia for the remainder of the pregnancy on strict bedrest, which would have been difficult since we already had a two-year old to take care of here in Massachusetts. In the end, we decided the risk of a premature birth outweighed the complications we were told to expect with a low level lesion SB child. Our daughter, Grace, is now four years old, has a shunt and is doing very well.

REFERENCE: Bruner JP, Tulipan N, et al. Intrauterine repair of spina bifida: Preoperative predictors of shunt-dependent hydrocephalus. American Journal of Obstetrics and Gynecology 2004; 190: 1305-1312.

HELPFUL AGENCIES

In occasional issues we will bring you news and information about Agencies and Organizations around the state and around the country, which provide services and assistance that may help you or your family member who has spina bifida. To offer suggestions of agencies or organizations we should include, please contact Hyacinth Bellerose (contact info on page 2).

Hospitality Homes
Hosting Patients' Families Since 1983

“The significance of affordable, convenient housing during a time of such stress and emotional pain is unparalleled. By simply providing a good night’s sleep in a warm, home environment you enabled me to better care for my sick loved one,” writes a Hospitality Homes guest from Maine.

When a loved one is sick, the presence and support of family and friends is critical. But when the best medical care is only available in a distant city, patients are often faced with the prospect of facing treatment far from home and far from their loved ones. Hospitality Homes works to ensure that patients traveling to Boston for medical treatment can do so with their loved ones by their side. By providing no-cost, short-term accommodations, the program offers an affordable alternative to lengthy hotel stays. With a network of over 100 volunteer host homes throughout the Boston area, Hospitality Homes provides not only a comfortable bed in which to sleep, but more importantly, a compassionate presence in an unfamiliar city and a welcoming home to return to at the end of a long day.

Since inception in 1983, Hospitality Homes has provided over 112,000 nights of guest housing. In 2003, guests came from 14 countries and 40 U.S. states and over 60% traveled to Boston seeking medical care for a child. Hospitality Homes is unique among Boston-area hospital housing programs because it is open to all families, regardless of income level, nationality, religion, or patient age, diagnosis, or treatment facility. All housing is provided at no cost.

To learn more about Hospitality Homes, visit < www.hosp.org > or call 1-888-595-HOST (4678). Applications for housing are taken over the phone, and it is recommended that potential guests call with as much lead time as possible (up to one month).

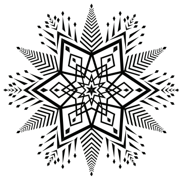
BITS AND PIECES

…from web sites to single events to quick tips…

Please submit Bits and Pieces to Hyacinth Bellerose (contact info on page 2)

BY HYACINTH BELLEROSE

- **2005 MSBA Benefits** – The MSBA has improved it's Benefits Program! An application for our new and exciting $1250.00 Benefits is available on Page 13 in this newsletter. Check it out, as well as the article about this year's upcoming Conference on page 7. See you in Minneapolis!
- **Sneakers Designed for AFOs** – They are here; sneakers that are designed specifically for children who wear braces. Designed by two Moms and a local brace company, Keeping Pace shoes are flat bottomed, have plenty of room for braces and look COOL! Check out their web site at < www.keepingpace.com > or call 1-888-526-0020 for a brochure. The first order of sneakers is due in the warehouse in November; the cost is $49.99. If this batch of sneakers sells well, the company will begin to produce other designs as well.
- **Parent Chat** – Our Parent Chat events at Barnes & Noble have not been a success. Many parents have shown an interest but the time or location didn't work for them. The MSBA is going to try to regionalize these events, but we need your input. Please contact Cara Packard (contact info inside front cover) by email or with a note or quick telephone call indicating (1) that you are interested in speaking with other parents; (2) where you live; (3) days of the week and times you could be available; and (4) the age of your child. It would benefit all of us to make this work, but we need your help.
- **Golf Tournament** – The MSBA's First Annual Golf Tournament will be held on June 2, 2005 at the Sky Meadow Country Club, just over the border in Nashua, NH. The Tournament and surrounding events are in the planning stages. If you have any experience with golf tournaments, know golfers who would participate or know of companies that might sponsor a hole or donate an item, please let us know. No doubt this will be a profitable fundraiser for the MSBA, but we will need your help & support to make it work!
- **Web sites for other chapters** – If you're in the mood for surfing the web but can't think of what sites to visit, check out the web sites of some of the other SBAA chapters and affiliates accross the U.S. A good place to start is the newly designed national web site at < www.sbaa.org >. Take a look around and then click on the Local Information button at the top of the page. Click on SBAA Group Members for a map followed by a list of chapters. Those chapters that have web sites have a clickable link. Also check out the "Links you can use" under "About Spina Bifida" (a left tab) and you will find an incredible amount of resources and interesting materials. If you find anything to share, send it to me and I'll include it here.
- **Partners for Youth with Disabilities** – Partners for Youth with Disabilities now has a secure online community at < www.pyd.org/partnersonline > for young adults (a left tab) and you will find an incredible amount of resources and interesting materials.
- **American Girl Doll Wheelchair** - American Girl Dolls ($84 each plus outfits for large doll; $40 for baby doll) are very popular and are now popular with me because I found out that they have a Wheelchair ($30). Even if you are not buying the doll, the wheelchair is made for an 18" doll so I would expect it could be used for any 18" doll. The contact information is as follows: Telephone number 1-800-845-0005 or web site: < www.americangirl.com >.



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

MSBA CALENDAR OF EVENTS

DATE	EVENT	LOCATION
November 1, 2004	Board of Directors Meeting	The Centres at Burlington
One Wednesday/Month	**MSBA Info Desk** at Myelo Clinic (Call MSBA or the Myelo Clinic for dates)	Children's Hospital, Boston
November 7, 2004	**Youth and Adults Group Gathering** 1:00 pm - 4:00 pm	Chili's Restaurant, West Springfield
December 4, 2004	**MSBA Holiday Party** 1:00 pm - 5:00 pm	Boston College Newton (Law School) Campus
December 6, 2004	Board of Directors Meeting	The Centres at Burlington
December 17, 2004	Winter Newsletter Deadline	To Cori Couture
January 3, 2005	Board of Directors Meeting	The Centres at Burlington
January 8, 2005	**MSBAYA Lunch and Learn**	Sturbridge Host Hotel, Sturbridge, MA
February 19, 2005	**MSBAYA Gathering (Event TBD)**	TBD
June 2, 2005	**First Annual MSBA Golf Tournament**	Sky Meadow Country Club Nashua, NH

Board Meeting Notes

Continued from page 13

Update starting on page 14.)

- **New and improved MSBA Benefits Programs!** We are happy to announce that MSBA members will be eligible for an Annual Conference Benefit of up to $750.00 — in addition to funds available through our regular Annual Benefits Program. Like last year, supplemental funding will be available, and is designed to encourage members to attend the SBAA's Annual Conference – this year in Minneapolis, Minnesota. In order to receive the maximum benefit, we will be asking members for community service and participation, in return for conference funding. *(For details, please see pages 12 & 13.)*
- **Revisions to MSBA By-Laws:** The Board of Directors recently completed revisions to the MSBA By-Laws. All changes were minor, and made for the purpose of clarifying general rules and procedures. If you are interested in seeing a copy, please contact Hyacinth Bellerose.
- **MSBA Holiday Party:** Plans for the MSBA's Annual Holiday Party are in full swing. This year's event will be held *at Boston College on Saturday, December 4, 2004 from 1-5 PM*. The MSBA would like to give a special thanks to Jen Fitz-Roy and The Boston College Disability Council for their help in making the party happen, and of course, for their wonderful hospitality!

  Be sure to *RSVP by November 26, 2004*! We need to know how many people will be in your group, as well as the ages of any children who will be participating. We look forward to seeing you there!

SPECIAL CONTRIBUTIONS

In Memory of ***George Marshall:***

- James & Jane Sagan, South Deerfield, MA
- James & Nancy Deming, Phillipston, MA

In Memory of ***George Hancock:***

- Paula & Warren Hancock, Kintenersville, PA

MASSACHUSETTS SPINA BIFIDA ASSOCIATION

733 Turnpike Street, #282
North Andover, MA 01845

Phone: 888-479-1900

Web Site: www.msbaweb.org

NEWSLETTER DEADLINE

DECEMBER 17, 2004

PLEASE SUBMIT ARTICLES AND INFORMATION FOR PUBLICATION TO:

CORI COUTURE
C/O MSBA
733 TURNPIKE STREET #282
NORTH ANDOVER, MA 01845
EMAIL: CORICOUTURE@FASTMAIL.FM

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. MSBA does not employ medical personnel in its organization.