MSBA NEWS

A PUBLICATION OF THE
MASSACHUSETTS SPINA BIFIDA ASSOCIATION

MEMBER, SPINA BIFIDA ASSOCIATION OF AMERICA

- SUMMER 2004 -

Some of the 36 MSBA Members that attended this year's SBAA Annual Conference in Washington, D.C. included (front row, l-r): Kevin Packard, Sarah Pinzino, Lindsay Meuse, (2nd row, l-r): Cori Couture, Jen Kuhar, Ginny Briggs, Betty Niedzwicki, Cara Packard, Aimee Shanks and Robyn Hand. (3rd row and back, l-r): Berta Pinzino, MaryAnn Brannigan, Matt Neal, Brian Packard, Steve Niedzwicki, Dominique Savinelli, Brandon Shanks, Sophia, Marc & Hyacinth Bellerose.

INSIDE THIS ISSUE

LETTER FROM THE PRESIDENT

BY BRIAN PACKARD

Greetings to all. I hope that you and your families are enjoying the fleeting days of our New England summer. This time of year seems to go by so fast. Thankfully, our spina bifida community has had some wonderful opportunities to get together this summer and celebrate the warmth of friendships and the warmth of the season.

We had an amazing turnout to the Spina Bifida Association of America's Annual Conference in Washington, D.C. in June. Over 35 members of the MSBA made the trip to conference this summer, far more than we have had in recent years. I think all who attended would agree that this year's event was jam-packed with exceptional presentations, meetings and social events. Once again, our multi-talented Editor-in-Chief, Cori Couture, gave a compelling

Continued on Page 3

MSBA OFFICERS

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

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

TREASURER
Brendan Sullivan 617-686-0696
514 Medford Street, Charlestown MA 02129
Email: ndsully01@yahoo.com

CLERK
Jennifer Kuhar 508-620-3963
1400 Worcester Road-Apt. 7519A
Framingham MA 01702
Email: jenkuhar@msn.com

BOARD OF DIRECTORS

Cori Couture 781-321-4920
Email: coricouture@yahoo.com

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

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

MSBA REGIONAL REPRESENTATIVES

SOUTHEASTERN MASSACHUSETTS

Aimee & Brandon Shanks
36 Laurel Street, Apt 1A
Whitman, MA 02382
Phone: 784-447-2707
Email: orchid502@yahoo.com

Patricia DeMoranville
334 Main St. Apt. 312B
Fairhaven, MA, 02719
Phone: 508-992-1484
Email: Pdcv1230@aol.

CENTRAL MASSACHUSETTS
Jean Cusick 508-756-3918
28 Camp Street Paxton, MA 01612

CAPE COD & THE ISLANDS
Judy Morgan 508-896-5085
36 Scarborough Road, Brewster MA 03631
Email: judjon1@comcast.net

WESTERN MASSACHUSETTS
Betty Niedzwiecki 413-774-3489
526 River Road, Deerfield MA 01342

NORTH SHORE / MERRIMAC VALLEY
Cindy Ward 978-682-9330
25 Devon Court, North Andover MA 01845
Email: Muna000@aol.com

M.S.B.A TELEPHONE 888-479-1900
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 www.geocities.com\HotSprings\2830

BENEFITS PROGRAM (Formerly "Camperships")
Joanne Mahoney 781-894-2749
98 Hibiscus Avenue, Waltham MA 02154
Cara Packard 978-683-6644
178 Hay Meadow Road, North Andover MA 01845
Email: packard44@comcast.net

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

MEMORIAL DONATIONS
Mary Ellen Shorey 508-881-5076
96 Pine Hill Road, Ashland MA 01721
Email: meshorey@attbi.com

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
Cori Couture 781-321-4920
Email: coricouture@yahoo.com

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

President's Letter
Continued from page 1

presentation entitled "Here's My Story – What's Yours?". As usual, it drew rave reviews from those in attendance!

The MSBA was also presented with several national awards:

Newsletter	1st Place
Programming (MSBAYA)	3rd Place
Fundraising (Marathon program)	3rd Place

Congratulations to everyone involved in making these programs and communications vehicles among the best in the spina bifida community nationwide. A special thanks to each member of the MSBA Board for helping to create an environment of excellence in all that we do.

Speaking of excellent, I hope you were among the 60+ MSBA members who gathered on a beautiful day on Boston Common this July for our annual MSBA Summer Picnic. We had a wonderful time playing baseball — let me tell you... wheelchairs and walkers stopped none of our players from rounding the bases after hits off our rookie pitcher, Marc Bellerose! For the tamer among us, there was croquet, and the kids enjoyed arts, crafts and face painting. Thanks to everyone who helped out with organizing the picnic. It really was a great time.

With the momentum the MSBA has right now, and on the heels of the National Conference, your MSBA Board continues to work hard to ensure our growth and energy is maintained long-term. On Sunday, August 22, we gathered for an all-day session to formalize our strategic plan. Among other topics, we discussed our organizational structure, awareness/service/advocacy priorities, community development programs, fundraising strategies and long-term vision. We intend to publish a summary of our strategic plan to the membership, and we will ask for your feedback.

After all, the MSBA is your organization. The Board has, and will always serve to meet the needs of the membership. So, stay tuned, and let us know what you think of the plans we put in front of you. Lastly, get involved! Help us become an even stronger organization by directly offering your ideas, time and service.

Best to each of you. I wish you health and happiness in the remaining days of summer.

Brian Packard

TEAM MSBA IN SAN DIEGO?

BY BRIAN PACKARD

Thanks and congratulations to Tom Reilly, nephew of MSBA members the Reidester family, for completing the San Diego Rock and Roll Marathon as part of Team MSBA. Tom donned the famous MSBA running singlet on June 6th and completed the run in 3 hours and 13 minutes. An impressive feat for a first-time runner. More impressive still is the fact that Tom raised $3,000 for the MSBA in the months leading up to the race. This represents the first time a member of Team MSBA has competed in a marathon other than Boston, and we hope this experience will serve as a model for our team's participation in marathons around the country in the coming years.

After the race, Tom said, "I will definitely do one again. It was a great experience. I highly recommend that the MSBA take the show on the road and run in San Diego if Boston is not available. I got about 20 compliments on that shirt you just can't miss. This was definitely a success."

We couldn't agree more. Thanks for the outstanding effort, Tom.

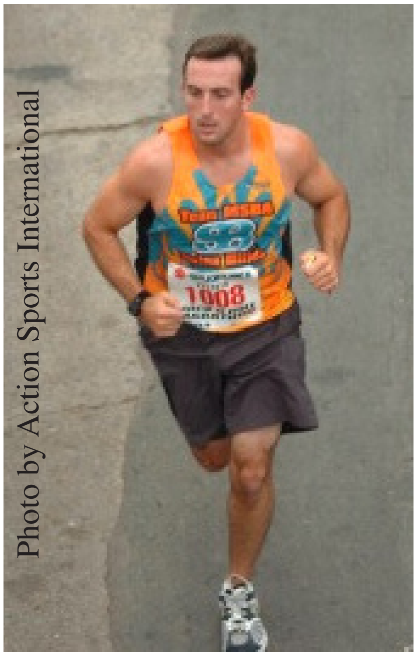


Photo by Action Sports International

New Team MSBA Member Tom Reilly on the race route for the Suzuki Rock 'n' Roll Marathon®, held in San Diego, CA, June 6, 2004.

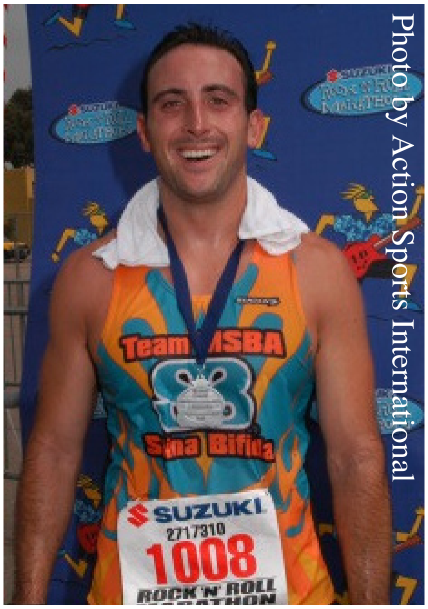


Photo by Action Sports International

Tom raised $3,000.00 for the MSBA and finished the race in pretty good shape, from the looks of him!

SBAA CONFERENCE 2004

BY DOMINIQUE SAVINELLI

The first time I had ever heard of the SBAA's annual conference was last year. I didn't go. Friends told me that San Antonio was great. Someone said that I should go at least once. With that advice in mind, I went to the Washington DC conference this past June. I was accompanied by an impressively high number of Massachusetts members (more than 35!) and am pleased to report that the conference has lived up to its reputation. Keeping in mind that everyone's experience is deeply personal, I'd like to highlight three benefits of attending conference.

First, the knowledge concentrated in one hotel was impressive and accessible! A group of well-informed, enthusiastic professionals imparted the latest information on spina bifida. Each session I attended dove into a specific topic with detail and focus. Sometimes technical, the information could be challenging, but nevertheless provided a good starting point for questions. There were always questions. To their credit, the speakers tried to answer as many as possible in each session. The range of topics spanned the social, medical, and scientific fields. To give you an idea, the diversity of topics included Sexuality for Adults, Cathing for Children, and the Genetics of Spina Bifida. There really was something for everyone.

The next benefit of conference was the unique opportunity to meet people from all over the country. People mingled and had fun. Some went sightseeing. Some swam in the pool. Others met over drinks. Lots of laughs were shared. Conference was a chance to form bonds with those from other states, swap stories and email addresses. It was a good time. Enough said.

Sarah Pinzino and Dominique Savinelli take a break from dancing at the opening night reception of the SBAA's annual conference in Washington, D.C.

Last, conference provides an opportunity for introspection, a look inside yourself. Our own Cori C. led a session on just this topic, where she bravely allowed the audience to explore her internal journey with spina bifida. For many of us, conference fosters a quiet reflection, and everyone will have a unique view. For me, I looked around at the collection of doctors, nurses, parents, and families. I went back in my mind to flashes of memory. My parents really had done so much, taking me to appointments, tests, and operations. My sister had always been there to protect and include me. I thought of my grandmother and my aunts doing dozens of things – from offering advice to hands on help. I thought of all the faces of hospital professionals. I can't remember their names anymore, but I do recall their smiles. I also thought of the other kids I met over the years, much sicker than me, with heart problems and cancer. These are things that I rarely have time to consider in my busy life now. Conference gave me the time to focus back to these memories of what makes me – me. I think that this chance to reflect is common at conference.

So, to end, I will say to you what was said to me last year. If you haven't ever gone to conference, go at least once. You won't regret it.

Members of the MSBA's Youth and Adults Group gather at the opening night reception (l-r): Sarah Pinzino, Sherry Evans, Aimee & Brandon Shanks, Dominique Savinelli , Robyn Hand, Jen Kuhar, and Lindsay Meuse.

EDITOR'S NOTE: IF YOU ARE INTERESTED IN ORDERING AUDIOTAPES OF ANY OF THE SESSIONS PRESENTED AT THIS YEAR'S SBAA CONFERENCE, PLEASE SEE THE ORDER FORM ON PAGES 15-16. IT INCLUDES A LISTING OF ALL AVAILABLE TAPES, PRICES AND ORDERING INFO.

SCENES FROM A PICNIC

BY DOMINIQUE SAVINELLI

This year's summer picnic was filled with relaxation and fun. Held July 17 on Boston Common, the day was beautiful, sunny and warm. Attendees included many of our young adults, families, and friends. There were toddlers and grandmothers, marathon runners and dogs.

As for activities, there were plenty! It was great to see people each doing their own thing. Several people brought lawn chairs and blankets, so they could just hang out and enjoy the day. Others chose to get active. There were games of baseball, frisbee, croquet and catch being played throughout the afternoon. It energized me just to watch the athletics with the group of spectators on the grass.

The kids lined up for face-painting. Soon they were running around with bright stars, fish, and flowers on their cheeks. There was food from KFC, music, and a general festive atmosphere. Overall, it was a great day for our members to talk, relax, and have a blast.

Katie and Daniel Packard, Carli Gordon and Dominique Savinelli work on art projects at the MSBA Summer Picnic, 2004.

The MSBA Board would like to thank the following for their donations and support for the picnic:

- Price Chopper in Shrewsbury
- Borders Books in Shrewsbury.
- Carli and Derek Gordon's Mom for her artful face painting.

MORE PICNIC PHOTOS, ON PAGE 17!

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 one of us.

- The first MSBA Golf Tournament has been scheduled!! It will take place on June 2, 2005 at the Sky Meadow Country Club in Nashua, New Hampshire. Stay tuned for more details! If you are interested in volunteering to help out or participating in the tournament, be sure to contact us.
- The summer picnic was a huge success. Thanks to all who participated. We are always looking for locations to hold our social events, so please contact us with your suggestions.
- The MSBA will begin hosting an information desk at Children's Hospital's Myelo Clinic one Wednesday each month from noon to 2:00pm. Please contact us for more details, as the schedule will vary from month to month.
- The MSBA Board of Directors held its annual strategic planning meeting on August 22, 2004. We will update you on the outcome of that meeting in the fall newsletter.
- The MSBA will be trade-marking the lovely new logo that we unveiled back in the spring.
- Brandon Shanks and Cori Couture continue to work on the MSBA website. They could use your help, particularly with graphic design and keeping content up to date. Please contact Cori if you would like to assist.
- On September 19, 2004, the MSBAYA Group will be gathering at Boston Beerworks, 112 Canal Street in Boston, starting at 3:30 PM to watch the Patriots Game. Please call the MSBA voicemail no later than Thursday September 16th if you plan to attend. You don't have to be a football fan to join us. We hope to see you there!
- In an effort to recruit new Board members and volunteeers, the MSBA recently registered for United Way Board Bank Online.
- We are still looking for a new home to hold our monthly meetings. If you know of a location that would be willing to help, please let us know. We are temporarily meeting at the Summerfield Suites in Waltham or at the Law offices of Hyacinth Bellerose in Tyngsboro.
- Preliminary planning for our annual Holiday party has already begun. Be sure to watch for more details.

WHO'S OUT THERE?

(MSBA MEMBER SPOTLIGHT)

THIS MONTH'S FEATURED MEMBER: DEIHLIA NYE

BY GINNY BRIGGS

Twenty-year-old, Deihlia (pronounced "Delia") Nye, is an active, independent student from Franklin, Massachusetts. She has the kind of drive and ambition most of us wish we had, even those of us for whom mobility is not a problem. She is a full-time student at St. Andrews Presbyterian College in Laurinburg, North Carolina, where she majors in Psychology. Her goal in life is to help other people, which is evident in her educational and career goals.

Deihlia insists her experiences as a child in school were not that different from anyone else's. She had friends, hobbies and interests just like other kids her age. She encountered some issues in the public school system that made getting around difficult, including chair lifts and the absence of elevators, but overcame these obstacles with a little motivation and creativity. Her one-story elementary school provided an easy place to get around, but things changed when she reached middle school where there was no alternative to the stairs. Luckily, she only needed to stay there one year, when the new middle school in town opened, which had an elevator. Her high school only had a chair lift, which was not reliable and often made her late for classes. Her teachers refused to excuse her early from classes to allow extra time for transporting herself upstairs. After that experience in her first year, she scheduled all her classes on the first floor, which solved the problem. One interest Deihlia always had throughout high school, was learning French, enough so that she became fluent and traveled to France with her class her senior year. Having a particular interest in art, she remembers getting to see impressionistic paintings as well as visiting such famous places as Paris and Normandy. She hopes to travel more, perhaps as part of a "study abroad" program at her college. Italy is of particular interest because of the abundance of art in that part of the world.

She chose St. Andrews College because she was looking for a small school with good wheelchair accessibility. Based on her research, she thought the school would be a good fit. However, she feels their literature and web site did not represent the campus accurately. After having to cancel a visit to the campus before entering as a freshman (due to a snowstorm), she didn't get to see for herself what accessibility was like. She feels most of the bathrooms are too small for a wheelchair and elevators are limited. This past year, she lived in an Adapted Daily Living (ADL) apartment which she enjoyed immensely. The apartment is designed to prepare students for independent living when they enter the outside world. However, there are only six apartments on campus, and she lost out to another student (unfairly, she believes) for the next academic year. As in her first year, she will be back in the "low rise" dorm this year, which has a single level and small bathrooms with narrow doorways. Though she is disappointed to have lost the ADL apartment this year, she feels the difficulties are worth it for the education she receives at St. Andrews. The classes are small and she gets plenty of individual attention from her professors. (The largest class has only about 20 students). To help herself and other students with disabilities, she plans to start a support group, which she'd like to call the "Adapted Student Union", a place and time for people to meet and share concerns and ideas.

Deihlia likes to think of herself, at this early age, as a "professional student". She plans to continue after college to a PhD program or perhaps even medical school. She has so many interests, she hasn't decided if she'd like to go into psychology, plastic surgery or some type of research. She shares her thoughts about the value and importance of these and other areas of medicine. However, she recommends visiting campuses before making decisions, especially to evaluate campus accessibility. Though it

has been difficult at times, she and her friends have been forced to come up with creative ideas to get Deihlia and her wheelchair where they need to be. Things have worked out, despite the various transport complications, but she thinks it's probably a good idea to verify the information put out by a college before getting on a plane.

This fall marks a turning point in Deihlia's life. Her mother (Donna) and sister (Chelsea, age 19) will be moving to Vermont to live with her new stepfather, John. Her mother just got married earlier this year and is expecting a baby boy in December. Deihlia is excited to have a father again in her life (her natural father died when she was eleven). She enjoys Brattleboro, Vermont and is looking forward to coming back from North Carolina for the holiday break to be with her new family in their new home. Meanwhile, her step-dad will be driving her back to North Carolina at the end of August, with a stop in Washington D.C. to visit the Smithsonian museums.

For fun, Deihlia enjoys reading, chess, video games and hopes to be involved with sports again. Growing up, she was involved with the Massachusetts Hospital School, where she was active in track and field. Since her grandmother bought a "Bob Hall" wheelchair for her last year, she feels basketball might be in her future as well. A "Bob Hall" wheelchair, as I have come to learn, is the wheelchair of wheelchairs. They are custom made for each individual who orders one. They are designed for height and weight, as well as preferences and needs, making them less bulky and more easily maneuvered. Deihlia's chair is lightweight (about 17 pounds) with easily removable wheels and a back handle for gripping after moving off the chair and into another seat. The chair is easily disassembled and put into the backseat of a car, so she is learning to drive this summer and hopes to bring her car back to college with her. This would allow much better mobility at school than she's had so far. Her insurance company did not cooperate in paying for this wheelchair (which was about $3,900), but she highly recommends it and feels it's worth it if you can find a way (including appealing the insurance company's decisions).

With an incredible, positive attitude, encouragement from her family and helpful friends at school, Deihlia is well on her way to a successful career and life. I was amazed at how comfortable she was at the idea of traveling, whether just back to school or to Europe for an entire semester. Her energetic commitment to getting everything out of life she can is remarkable and admirable. Stand back, Deihlia Nye is going places.

PUBLIC AWARENESS CORNER

BY DOMINIQUE SAVINELLI

Time for school is HERE! With the arrival of fall, the SBAA has provided us with some great bookmarks and we need you to help us distribute them. These colorful, informative bookmarks promote awareness of spina bifida, folic acid, and the Spina Bifida Association of America. They are also useful – especially for new students. Please help us get the word out to local colleges and even high schools in your area. Distributing these bookmarks is a quick, easy way spread awareness of spina bifida. To have a stack sent to you, please call the MSBA or email me at dominiquesavinelli@hotmail.com, with your name and address. I will send you some right away. Thanks, in advance, for your help!

Grace Briggs-Neal and new friend Carli Gordon play hide and seek at the MSBA Picnic on Boston Common

MEDICAL RESEARCH CORNER

BY GINNY BRIGGS

RATES OF HEALTH PROBLEMS EXPERIENCED BY YOUNG ADULTS WITH SPINA BIFIDA

A study was recently conducted in the Netherlands examining health problems experienced by young adults with spina bifida (SB). The goal was to divide people with SB into categories and look at the incidence of such complications as shunt revisions, decompression surgeries, tethered cords, scoliosis, urological surgeries, incontinence and sexual function. The study included those with any type of SB, with or without hydrocephalus, including SB occulta (abnormal spine development that usually doesn't involve the nerves) . Of the 350 SB cases located, 179 were willing and able to participate in the study, 41% male and 59% female, all aged between 16 and 25 years old. All the participants were interviewed and examined by a physician.

The results of the study were analyzed in two ways. First, the cases were divided into three groups: SB with hydrocephalus, SB without hydrocephalus and SB occulta. Second, the cases were divided into another three groups, by level of their lesion: "high level" (L-2 and above), "mid-level" (L-3 to L-5) and "low level" (S-1 and below). The results are presented in the tables below:

Most of the patients (60%) used clean intermittent self-catheterization, some were dependent on others for catheterization and others used other methods. 25% of the total group never had accidents of urine leakage, 13% had accidents less than once a month, 24% had monthly accidents, 11% had weekly accidents and 26% had daily accidents. About half of the total group experienced urinary incontinence as a problem. Almost one third of all patients used low doses of antibiotics continuously. In the two years before this study, about two thirds of all patients needed a course of antibiotics to treat urinary tract infections. 36% needed antibiotics one to two times in two years, 50% needed it three to five times and 14% needed it more than 5 times.

To summarize the results, those in the high-level lesion

Table 1: Percentages of SB patients with various complications as related to type of SB

Complication	SB with hydrocephalus (119 cases)	SB without hydrocephalus (23 cases)	SB occulta (37 cases)
Shunt revisions	84%	0%	0%
Cervical decompression	10%	0%	0%
Tethered cord surgery	18%	39%	68%
Scoliosis surgery	27%	4%	8%
Lower extremities surgery	68%	39%	38%
Urological surgery	50%	61%	14%
Epilepsy	9%	0%	3%
IQ ≤ 70	20%	0%	3%
Pain	25%	26%	35%
Spasticity	13%	0%	0%
Lumbar lordosis	39%	15%	6%
Sitting balance deficit	19%	0%	0%
Contractures, hip (range of motion limitations)	18%	0%	0%
Contractures, knee (range of motion limitations)	36%	5%	3%
Foot deformities	85%	45%	49%
Urinary incontinence	71%	52%	35%
Fecal incontinence	46%	13%	85%
Males sexually active	60%	93%	100%
- problems with erections	29%	8%	0%
- problems with ejaculation	39%	15%	0%
- problems with orgasm	43%	8%	0%
Females sexually active	46%	89%	88%
- problems with lubrication	6%	0%	14%
- problems with orgasm	47%	38%	23%

Table 2: Percentages of SB patients with various complications as related to level of lesion

Complication	High-level lesion (L-2 and above) (73 cases)	Mid-level lesion (L-3 to L-5) (68 cases)	Low-level lesion (S-1 and below) (38 cases)
Shunt revisions	78%	57%	11%
Cervical decompression	10%	6%	3%
Tethered cord surgery	23%	25%	55%
Scoliosis surgery	41%	6%	5%
Lower extremities surgery	71%	68%	13%``
Urological surgery	55%	40%	32%
Epilepsy	13%	3%	3%
IQ ≤ 70	22%	9%	6%
Pain	26%	29%	26%
Spasticity	15%	6%	0%
Lumbar lordosis	50%	22%	0%
Sitting balance deficit	29%	2%	0%
Contractures, hip (range of motion limitations)	28%	2%	0%
Contractures, knee (range of motion limitations)	46%	15%	0%
Foot deformities	86%	86%	20%
Urinary incontinence	70%	68%	32%
Fecal incontinence	45%	34%	13%
Males sexually active	46%	86%	94%
- problems with erections	39%	16%	0%
- problems with ejaculation	54%	24%	0%
- problems with orgasm	54%	20%	7%
Females sexually active	44%	66%	82%
- problems with lubrication	5%	12%	6%
- problems with orgasm	47%	36%	28%

group and those in the hydrocephalus group had more problems in general. Also, those with SB occulta showed similar complications to the other two groups. Most studies to date have not included SB occulta cases, so this indicates a need for further research on people with SB occulta.

It should be noted that, as with all studies, this study has several limitations to consider. First, assessing the level of the lesion is complicated and not always completely accurate, so it's possible that some people were not placed in the right group. Second, this study was done on a Dutch population only. It is possible that differences in culture and medical care could have affected the rates in the tables above. For example, the rate of urinary tract infections or shunt revisions may be lower or higher in other populations. Third, much of the information was given through self-reporting by patients, so some answers may have been inaccurate. It has been found that self-reporting can be affected by problems with remembering things accurately and, due to the personal nature of some of the questions in this study, some may have been reluctant or embarrassed to answer some questions. However, there haven't been many studies published that have reported long-term outcome of people with spina bifida, so these results can be useful to some as a guideline.

REFERENCE: Verhoef M., Barf HA, et al. Secondary impairments in young adults with spina bifida. Dev Med Child Neurol. 2004 Jun; 46 (6):420-7.

Please Note: *The contents of this column are for informational purposes only and are not intended to replace medical diagnosis or treatment. The MSBA does not diagnose medical conditions, offer medical advice or endorse specific products, services, procedures or companies. If you would like to know if the information in the article is appropriate for you, please consult your medical doctor.*

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, a 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 website at www.msbaweb.org for ongoing events and programs.
- In order to receive the MSBA's newsletter, the SBAA's quarterly newsletter *Insights*, and to receive other MSBA benefits, it is necessary to be a 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 .

- Please note that MSBA financial benefits are available only to members who (1) have spina bifida, and (2) live in Massachusetts or in a New England state that does not have its own spina bifida association.
- 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, PLEASE SEND YOUR EMAIL ADDRESS TO HYACINTH BELLEROSE AT BELLEROSE33@CHARTER.NET.

MSBA MEMBERSHIP APPLICATION/UPDATE FORM

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

Type of Membership:

- ___ Teen or Adult with spina bifida
- ___ Parent(s) of Child with spina bifida (Family Membership)
- ___ 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 Name : ____________________

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 **

BY HYACINTH BELLEROSE

Are you aware of the MSBA Benefits Program? Did you know that if you are a Qualified Member of our association you may be eligible for $500 each year? Or that you may be eligible for additional funding toward attending the Annual Spina Bifida Association of America conference in the summer? See the policy below to find out more.

What constitutes a Qualified Member? A person with spina bifida or the parent/guardian of a person with spina bifida, who resides in Massachusetts or in a state bordering Massachusetts that does not have its own Spina Bifida association, and whose information is up to date in the MSBA database. 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 per year to be used to improve his/her life as it is affected by spina bifida. These Annual Benefit funds may be used for braces, diapers, summer camp, assistive technology, education or similar purposes. An application must be submitted to the MSBA via postal mail or by Email and will be reviewed by the Board of Directors at the following month's Board meeting. Once the application has been approved, there are two ways for a Qualified Member to receive Benefit funds.

1. The Qualified Member may present a receipt showing payment of an eligible expense already incurred. Once this receipt is received, the MSBA will write a check to be paid to the Qualified Member as reimbursement. OR
2. Alternatively, a bill or invoice for the eligible expense *to be* incurred may be presented to the Board in advance. In this case, the MSBA will write a check directly to the benefit provider or vendor for the expense in question.

The MSBA reserves the right to revise this policy in accordance with the changing financial position of the MSBA.

This year, Qualified Members were entitled to *an additional $500*, to be used expressly for expenses related to attending the SBAA Annual Conference in Washington, D.C. back in June. This experimental program was extraordinarily successful (over 35 MSBA members attended this year's conference), so the Board of Directors is discussing similar plans for next summer's conference. Watch this space for details.

MSBA BENEFITS FORM

Name: ______________________

Street Address: ____

City, State, Zip: ____

Telephone: ____________________ **Email**: _________________________________

Check as Applicable:

___ Request for Annual Benefit of $500
    ___ Receipt Attached
    ___ Make check payable to enclosed provider

Provider Information:

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

START EARLY, FIGHT HARD

BY CHERYL SMITH

One of the greatest lessons I learned with transitional planning is that it's never too early to start to plan the "rest of your life". My son Brian's goal for his ITP (Independence Transition Plan) was that "we were not going to live together for the rest of our lives". While I love both my children, I knew I would not and could not live with them 24/7 as they grew older. So, that was our motivation as we began the transition planning process.

When Brian was 16, I initiated meetings at both DMR and Mass. Rehab. Although the school system where he had grown up was still responsible for services, I wanted other agencies that perhaps Brian would be involved with as an adult to be part of our IEP (Individualized Education Plan)/ITP meetings. We looked to our school system for transition programs that could help us accomplish our goals. They knew of none, although they were ready to release Brian into the adult world of services when he graduated. MOM WASN'T.

We refused his High School diploma and stated that Brian was still in need of services until he turned 22. We found a program on Cape Cod at the Riverview School that would help him learn life skills in a safe and secure environment. He would be with students much like himself, who were able to learn, but who needed additional time, training and supervision. Brian was also enrolled in Project Forward, a vocational program housed at Cape Cod Community College that has programs for students with learning disabilities. These programs include culinary studies, retail, animal care, and buildings and grounds maintenance, to name a few.

While it was a fight to get the school system to pay for the programs Brian needed, we accomplished this by relying on information from the Department of Education and avoided the cost of expensive lawyers. After two years, Brian received certificates from both programs and walked tall, with greater self-esteem, more confidence and wonderful new friends from all around the world.

Upon reaching age 22, Brian decided that he wanted to continue to reside on the Cape. We managed this by transferring services provided by DMR and Mass Rehab in our home area to the agencies' offices in Hyannis.

Brian currently resides at TGI (Towards Greater Independence) in Centerville, MA, and is supervised by a woman named Colleen Cahill. Through Colleen, Brian receives supervision and assistance (sometimes wanted and sometimes unwanted) in areas that include medical services, nutrition, transportation, and budgeting. His apartment is located adjacent to Colleen's premises, which offers me a sense of security about his well being. (Keep in mind that Brian, as a young adult, DOES NOT value this attention the same way as his mother does.)

In getting Brian to this stage of independence, we learned many things. One of these is that the processes involved in qualifying for DMR services as a child are much different than qualifying for services as an adult. Brian needed to go through a whole series of interviews and testing and was just borderline for being accepted to receive services at all. Completing this process took many months.

When Brian graduated from Riverview, I spoke with many parents who assumed that their young adults would qualify for assistance, and were devastated when they received letters saying they wouldn't. All denials were due to the fact that their children had IQs above 70. Since their children had qualified for youth services, they assumed they would also qualify for adult services, but this was not true. Many parents had waited to start the qualification process until the year their child turned 22 and had no back up plans.

We, as parents, knew these young people were unlikely to be able to take care of themselves alone in the real world. In many cases, the adult children of these disappointed parents would be coming home to live with them. The parents would continue to be the only ones helping them to look for work. The parents would also, in many cases, continue to be the providers of care, or the ones who would be in charge of seeking continued support services for their grown children.

I started these processes the year Brian turned 18. In addition to the steps mentioned earlier, I also worked to get Brian a housing voucher to assist in paying his rent. (This voucher can be transferable between communities.) His $800.00/month rent is currently subsidized by $533.00, allowing him to personally pay $277.00. Acquiring this voucher — again — took us several months.

Once Brian qualified for adult services, I informed DMR that I would no longer be responsible for him when he turned 22, and basically, that he would be at the mercy of the state. Sounds cruel doesn't it?

While DMR did inform me that Brian could remain at home and I could be paid to provide services, I knew this was not Brian's goal! We each needed to have our separate lives.

While I am still Brian's biggest advocate, he is starting to learn to rely on others when he needs assistance. We frequently discuss what he perceives his needs to be as opposed to what Mom perceives his needs to be.

Brian works part-time at Home Depot, receives no SSI, but is able to be covered by Masshealth — thank goodness! He has a close circle of friends and seems to really be enjoying life. He's starting to figure out what budgeting really is and has found that if he doesn't keep his place clean, he doesn't get to go out fishing on Sundays with his landlord. Isn't motivation a wonderful thing?

Bottom line: Start early, fight hard.

Cheryl Smith is Town Accountant for the town of Concord, MA, is a former Treasurer of the MSBA, and proud mother of Brian, 23, of Centerville, MA. You can contact her at vze2hccx@verizon.net.

MSBA YOUTH AND ADULTS GROUP (MSBAYA) UPDATE

BY BRENDAN SULLIVAN

Well, there has been quite a bit of flurry within the MSBA and the MSBAYA since the last newsletter. There was a strong group of MSBAYA members at the many Marathon events in April. Speaking on behalf of the runners, I know seeing all those people in West Natick cheering TEAM MSBA on and again at the reception at the Westin Hotel was a great lift. In both instances, it eased the pain and made those steps a little easier to take.

MSBAYA members get to know folks from other chapters at a reception hosted by the SBAA Youth and Adult Alliance on Monday night of the annual conference in Washington, D.C. Pictured here left to right: MSBAYAers Jen Kuhar, Brandon & Aime Shanks with Jesus Aroyo of the Colorado SBA.

After the Marathon festivities, the group met on its own in early June for a day of board games and fun. Seems childish right? Well it was far from it! Craig Swanson (Cori Couture's husband) came with an array of interesting and modern games that kept the fifteen of us there very entertained and, I must say, very challenged. In fact, the group was so entertained we ran well past our allotted time of 4 hours! A successful day nonetheless and we hope to have more people at what I think will be a regular fixture on the MSBAYA calendar.

Next, came the annual MSBA picnic, which was held on Boston Common this year. Though they left the face painting and baseball to the kids, many MSBAYA members made it to the picnic and enjoyed a beautiful summer day in the shadows of downtown Boston's skyscrapers. For most, the day was spent talking and catching up with other MSBA members and enjoying good old-fashioned BBQ food provided by KFC!

The next event planned for the MSBAYA group is to catch the fever along with the rest of New England and cheer on the New England Patriots this season. The group will be gathering on Sunday, September 19th at Boston Beer Works near North Station, in Boston. The group will begin gathering at 3:30 p.m. for the 4:00 p.m. game to ensure we get an area with prime viewing of the TV's. Boston Beer Works is located at 112 Canal Street in Boston, is wheelchair accessible as well as T accessible (North Station stop on the Green Line). So, please come join us for this afternoon of food, football, and friends. Even if you don't like football this is a great chance to meet new people and chat for a few hours. And, who knows you may walk out a Patriot and football fan, (ahem, Dominique). More information about this event is coming your way soon via email and flyer.

Katie Hoffman of Indiana SBA (2nd from left) socializes with MSBAYAers (l to r) Robyn Hand, Sarah Pinzino, Sherry Evans and Lindsay Meuse during the SBAAYAA Conference Reception.

MSBA YOUTH AND ADULTS GROUP CONTACT INFO

Cori Couture
Phone: 781-321-4920
Email: coricouture@yahoo.com

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

Dominique Savinelli
Email: dominiqueSavinelli@hotmail.com

Brendan Sullivan
Phone: 617-241-8561
Email: ndsully01@yahoo.com

- ORDER TAPES OF SBAA CONFERENCE SESSIONS -

SPINA BIFIDA ASSOCIATION ORDER FORM
2004 ANNUAL CONFERENCE – WASHINGTON D.C.

SPECIAL OFFERS – SAVE YOU $$$
ANY 12 TAPES FOR $88.00: GET 1 TAPE FREE & 1 FREE STORAGE ALBUM
ANY 24 TAPES FOR $176.00: GET 2 TAPES FREE & 2 FREE STORAGE ALBUMS

Quantity	Code	Cost	Individual Cassettes are $8.00 each
			MONDAY, JUNE 21 SESSIONS
	W-1	$16.00	Plenary Session: Transitions, *Brei, Cordero, Cheng, Dias, Zahra, Merkens, Simeonsson, Fletcher, Sawin and Tosi* **(2 tapes)**
	W-2	$8.00	Anxiety and Depression in Adults and Children with Spina Bifida, *Liptak*
	W-3	$8.00	Learning and The Brain, *Fletcher*
	W-4	$8.00	Latex Allergy, *Elli Meeropol*
	W-5	$8.00	Tethering, *Dias*
	W-6	$8.00	MOMS – Fetal Surgery Study, *Shaer*
	W-7	$8.00	Proper Wheelchair and Seating, *Thieme*
			TUESDAY, JUNE 22 SESSIONS
	W-8	$8.00	Health Care Issues for Adults with Spina Bifida, *Timothy Brei & Mark Merkens*
	W-9	$8.00	Psych/Neuropsych Evals: What to Look for… *Baron*
	W-10	$8.00	Chiari Malformation and Syringomyelia, *Piatt*
	W-11	$8.00	The Art of Self-Catheterization, *Brown*
	W-13	$8.00	Male Sexuality, *Rovner*
	W-14	$8.00	Developmental Changes, *Simeonsson*
	W-15	$8.00	Effective Hydrocephalus Management in the Patient with Spina Bifida, *Jallo*
	W-16	$8.00	Skin and Wound Care, *Frost*
	W-17	$8.00	Fathering a Child with Spina Bifida, *Horowitz*
	W-19	$8.00	Ask The Doctor: Effective Urologic Care
	W-20	$8.00	Ask The Doctor: Neurosurgical Issues Related to Shunting, *Dias/Muraszko*
	W-21	$8.00	Issues for Women with Spina Bifida: Adolescence to Aging, *Jackson and Sawin*
	W-22	$8.00	Schooling and Education, *Simeonsson*
	W-23	$8.00	Surgical Options for the Bowel and Bladder, *Cheng*
	W-24	$8.00	Genetics and Spina Bifida: Update, *Melvin, Siegel, Speer, George*
	W-25	$8.00	Ask the Doctor – Orthopedic Concerns, *Rathjen*
	W-27	$8.00	Urologic Issues in Adolescents and Adults, *Rovner*
	W-28	$8.00	Psychosocial Adjustment, *Holmbeck*
	W-29	$8.00	Management of the Neurogenic Bowel, Jean Brown
	W-30	$8.00	Spinal Deformity, *Rathjen*
			WEDNESDAY, JUNE 23 SESSIONS
	W-32	$8.00	Psychosocial Outcomes of Spina Bifida in Adulthood, *Erickson*
	W-33	$8.00	NLD from NeuroPsych Perspective, *Fantie*
	W-34	$8.00	Independence Lessons Learned from a Project on Socialization for Teens, *Rauen*
	W-35	$8.00	Lipomyelomeningocele, *Kanev*
	W-36	$8.00	Special Education – Federal Perspective, *Scott Brown*
	W-37	$8.00	Family Centered Parenting, *Horowitz*
	W-38	$8.00	Recruiting, Developing and Training – Preparing Teens and Young Adults to Serve on SBA Boards, *Mayeux*
	W-39	$8.00	Spina Bifida Difficulties Impact Outside School, *Brei*

			WEDNESDAY, JUNE 23 SESSIONS CONTINUED
Quantity	**Code**	**Cost**	**Individual Cassettes are $8.00 each**
	W-40	$8.00	Urologic Management in Infants, *Pohl*
	W-41	$8.00	Sexuality and Spina Bifida For Parents, *Sloan*
	W-42	$8.00	Primary Prevention Outreach, *Flores/Griffen*
	W-44	$8.00	My Story, *Couture*
	W-45	$8.00	Sexuality and Spina Bifida In Adults, *Sloan*
	W-46	$8.00	Spina Bifida Awareness, *Griffin*
	W-47	$8.00	The Need for Parent Support Groups in a Clinic Setting, *Mizokawa/Goldfarb*
	W-49	$8.00	Creating a Healthcare Home for Adults with Spina Bifida, *Mayeux*

Quantity Ordered	Price	
		INDIVIDUAL TAPES: **# ORDERED X $8.00 Each**
	88.00	**12 TAPE SPECIAL: Any 12 Tapes for the price of 11, plus a FREE storage album**
	176.00	**24 TAPE SPECIAL: Any 24 tapes for the price of 22, plus two FREE storage albums**
	360.00	**FULL SET: Includes all conference tapes, receive 5 FREE tapes, plus FREE albums**
		Total Amount for Cassettes
		Empty Storage album that holds 12 tapes @ $7.00 each
		Sales Tax is .0725% but only for orders shipped to Illinois
		Shipping: $3.50 for 1 tape, $1.00 for each additional tape. Maximum $14.50 Domestic. No maximum for International.
		GRAND TOTAL OF ORDER

WE ACCEPT CASH, CHECK (PAYABLE TO FIRST TAPE), VISA, MC, OR AMERICAN EXPRESS

PLEASE DO NOT FILL IN CREDIT CARD INFORMATION UNLESS ORDERING BY MAIL OR FAX

Your Credit Card No. _ _ _ _/ _ _ _ _/ _ _ _ _/ _ _ _ _ Expiration Date: _ _/ _ _

For VISA Cards: I.D. Code __ __ __ (Last 3 digits on signature line, back of card)

Name		
Street		
City	**State**	**Zip**
Telephone	**Fax**	
Signature	**Email:**	

MAIL OR FAX TO: FIRST TAPE, INC., 21 SMITH LANE, SOUTH BELOIT IL 61080
Telephone: 815-389-1818 Fax: 815-389-1418
E-mail: firsttapeinc@aol.com

FOR CASHIER USE ONLY: PAID BY: [ ] Cash/ Check payable to First Tape [ ] Visa/MC [ ] Amer Express

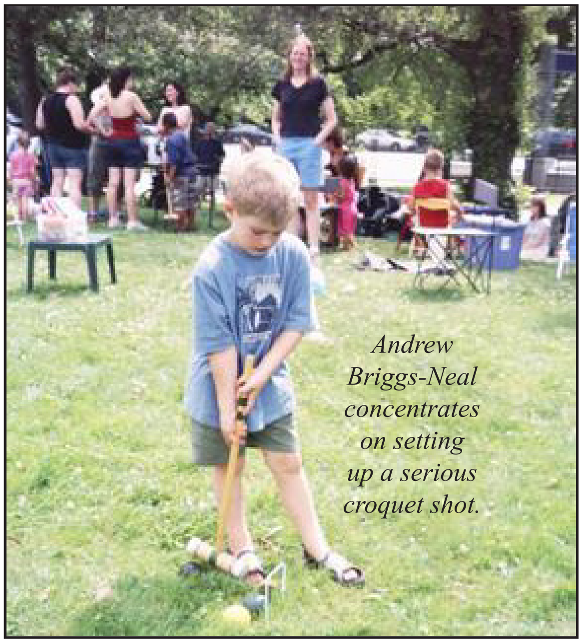
Picked up: **Ship:**

MSBA Summer Picnic - July 17, 2004 - Boston Common

New member Elaina Cardenas gets the scoop on the MSBA from old-timer Daniel Packard.

(bottom to top): Aimee Shanks, Melissa Spillere, Jen Kuhar, and Nichole Valois stretch out on the grass, while watching the kids play ball.

Outfielders Derek Gordon and Matt Neal look on as Team MSBA Trainer Dominic D'Amico fires off a smokin' pitch.



Andrew Briggs-Neal concentrates on setting up a serious croquet shot.

Carli Gordon pets Oakley, MSBA mascott for the day, while Oakley's owner and Team MSBA runner Dave Balardini chats with Brian and Kevin Packard.

Relaxing and chatting under a shady tree are (l-r): Daryl Perpignan, Lindsay Meuse, Brendan Sullivan with his mom Anne, Brian & Katie Packard, and Robyn Hand.

BITS AND PIECES

….from websites to single events to quick tips…

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

BY HYACINTH BELLEROSE

- **Parent Chat Groups** – The next Parent Chat Group meeting is on September 14, 2004 at the Barnes & Noble Café, 98 Middlesex Road, Burlington, MA (across from the Burlington Mall). We are open to suggestions from parents for dates, times and places to meet. We want to be where you need us to be!!!! Contact Cara Packard or Hyacinth Bellerose for more information. (See page 2 for our contact info.)

- **Children's Hospital Chat Groups** – After speaking with Maryjo Dunleavy, the Myelo clinic coordinator at Children's, our Parent chat groups will be based on the number of families attending clinic on any given Wednesday, rather than on a pre-set Wednesday each month. We would like to alleviate some of the stress of waiting for clinic appoinments, and reach out to as many people as possible, so we will be attending on the busier day each month. Hope to see you there!!!

- **Nonverbal Learning Disabilities Conference** – September 15, 2005 at the Wyndham Westboro Hotel (8:00am to 4:00pm, refreshments provided, $115.00). Check out www.mapleleafcenter.com or call 802-446-3601 for more information. The Maple Leaf Center website lists many publications on the subject of NVLD.

- **Autumn in New England** – Check out the following website: http://members.aol.com/newenglandcamper/camping/nefaire.html, for a listing of New England Fairs and Festivals, Apple Picking Locations, New England Foliage Links, Pumkin Fun, Hay Rides and Factory Tour Info. If you do not have access to a computer at home, go to your local library for assistance in pulling up this website. There are a lot of fun events going on this fall!

- **Sibling Research Project** – Volunteers 11-18 years of age who have a brother or sister with spina bifida, along with a parent, are needed to take part in a study conducted through the Virginia Commonwealth University. Contact Melissa Bellin, the social work doctoral student conducting the study, for more information:
  Email: mahayden@mail1.vcu.edu; Phone: 301-528-4149 or 800-484-7508 (pin 1272).

- **DCR Access "Integrating People of All Abilities into State Parks" Newsletter** – The DCR is the Massachusetts Department of Conservation and Recreation (formerly the MDC). Contact Gigi Rano, Program Director at 617-626-1294 to get on the mailing list for the DCR's newsletter. It's packed with information about state parks and outdoor events in Massachusetts geared towards people with mobility issues. Check out their website at www.mass.gov/dem/a_events.htm or email gigi.ranno@state.ma.us. Get outside and have some fun!!!

- **Adolescent Community Mobility Project** This is a Boston University student project to better understand how well adolescents with mobility limitations to get to and participate in activities after school, with an end goal of to enhancing their community participation. For more info, contact Diana Goldstein at 800-484-6776 (Pin 9755) or Email: dngold@bu.edu.

- **Dolls with Braces** – To learn about these dolls with realistic braces and crutches, check out: http://milwaukee.brace.nu/text/doll.html

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
September 13, 2004	Board of Directors Meeting	Tyngsboro, MA
September 14, 2004	**Parent Chat Group** 7:00 pm (2nd Tuesday of every other month)	Barnes & Noble, Burlington, MA
One Wednesday/Month	**MSBA Info Desk** at Myelo Clinic (Call MSBA or the Myelo Clinic for dates)	Children's Hospital, Boston
September 19, 2004	**Youth and Adults Group Gathering** 3:30 pm to watch Patriot's game	Boston Beerworks, 112 Canal St., Boston
October 4, 2004	**Board Meeting**	TBA
October 8, 2004	**Fall Newsletter Deadline**	To Cori Couture
November 1, 2004	**Board of Directors Meeting**	TBA

MSBA NEWS WINS FIRST PLACE

As Brian Packard mentioned in his President's Letter, MSBA News garnered first place in the newsletter category at the SBAA's annual conference Awards in Washington, DC in June. I'm proud that we've been able to continue a tradition of excellence, set by former Newsletter Editor Amy Constantino, who won the top prize 2 years ago in Orlando.

My heartfelt thanks go out to Mike Higgins, who co-edited the Fall and Winter issues. Also, there would be no newsletter without the regular and thoughtful articles contributed by members of the Board. You guys are wonderful.

Thanks also to the organizations and agencies who have sent articles and information about the many fantastic programs and services you offer around the state. Keep them coming!

Finally, applause to all our members who have contributed articles and ideas to the newsletter. I strongly encourage you to take a few moments to write down your thoughts and experiences, and send them along for inclusion in the newsletter. Not big on writing? No problem - photos, drawings, or suggestions for articles or other features are always welcome. If you have something you'd like to contribute to the newsletter, or something you'd like us to include, please speak up.

You can always email me at coricouture@yahoo.com.

Cori

MASSACHUSETTS SPINA BIFIDA ASSOCIATION
733 Turnpike Street, #282
North Andover, MA 01845
Phone: 888-479-1900
Web Site: www.msbaweb.org

NEWSLETTER DEADLINE

OCTOBER 8, 2004

PLEASE SUBMIT ARTICLES AND INFORMATION FOR PUBLICATION TO:

CORI COUTURE
C/O MSBA
733 TURNPIKE STREET #282
NORTH ANDOVER, MA 01845
EMAIL: CORICOUTURE@YAHOO.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. MSBA does not employ medical personnel in its organization.