MSBA NEWS

A PUBLICATION OF THE
MASSACHUSETTS SPINA BIFIDA ASSOCIATION

MEMBER, SPINA BIFIDA ASSOCIATION OF AMERICA

- SUMMER 2005 -

INSIDE THIS ISSUE

IT'S BEEN A BUSY SUMMER!

SBAA Annual Conference 2005
Minneapolis. MN
See pages 4 & 5 for a recap & Photos

MSBA First Annual Golf Tournament
Nashua, NH
See pag 6 for a recap & Photos

MSBA Annual Summer Picnic
Cambridge, MA
See pag 7 for a recap & Photos

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Email: mozzas@comcast.net

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

LETTER FROM THE PRESIDENT

BY BRIAN PACKARD

Happy summer to each of you!

The MSBA welcomed the season's beautiful weather with our **Annual Summer Picnic** on July 23rd at Danehy Park in Cambridge. Roughly 75 members gathered for a relaxing day at the park to catch up with friends, while the kids enjoyed crafts and the park's great facilities. Thanks to Cara Packard for organizing a great day, and to all those who coordinated food donations, carpools and activities. The MSBA Board used the gathering to announce this year's winner of the **Jean Driscoll Scholarship**, **Erin Murphy**. Congratulations Erin!

Earlier this summer, many of us (nearly 20) attended the **SBAA Annual Conference** in Minneapolis June 26-29. As usual, the conference was chock-full of informational programming and social activities. This year also featured a new Adults Day - a program devoted just to adults with spina bifida - alongside the Group Member Day on Sunday. Both these programs as well as the regular conference sessions were well-received among the 800+ attendees. Our delegates to the conference commented that our national organization has made great strides in recent years, both in terms of financial health and organizational strength. During the Awards Luncheon, the MSBA picked up numerous **awards,** including **first place for our public relations efforts surrounding Brendan Sullivan's Boston Marathon run as part of Team MSBA**. We also received awards for *MSBA News*, MSBAYA programming and our marathon fundraising program.

In addition, **Elli Meeropol**, Nurse Coordinator of the Shriner's Clinic in Springfield **received a Lifetime Acheivement Award**. Elli is retiring from medicine and will be sorely missed by patients and families alike. Watch the fall newsletter for more about Elli.

We held our **First Annual MSBA Golf Tournament** on June 2nd at the Sky Meadow Country Club in Nashua, NH. The event was a great success, with most of the 38 golfers saying they would be back next year with lots of friends. Hyacinth Bellerose did a terrific job of organizing the day, putting in countless hours to ensure the tournament was a successful fundraiser and public awareness event. We all look forward to an even bigger tournament next year, and hope to make this event a regular part of our fundraising and community outreach efforts in the future.

The **MSBA Youth and Adults Group** has been very active this summer, getting together in June at Children's Hospital Boston for Board Game Day, followed by a large group attending the National Conference in Minneapolis, many for the first time. The MSBAYA is having a bowling day on August 13th and is planning a sports clinic in late September. This group continues to flourish and grow, with more than 90 active members now participating in online chats, regular events and informal gatherings.

Organizationally, the MSBA Board has completed our **Strategic Plan** and is moving forward to implement programs we have identified as our highest priorities. Please take a moment to visit our web site (www.msbaweb.org), where the plan is now available for viewing. We would love to hear your comments on the goals and strategies we have set for ourselves in the areas of funding, organizational capacity, awareness/education, advocacy, community and support/services. We have also begun to list areas where we need your help in a "Volunteers Needed" section. If you or anyone you know would like to help out with any of the areas listed, follow the link and get involved! And remember, please check the site regularly, as it will now be the updated central source for all the latest news and events of the MSBA.

It's been a great summer so far, and I wish each of you fun, health and happiness in the months ahead. — *Brian Packard*

MSBA VOLUNTEER OPPORTUNITIES

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

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

Frank Pote of the SBAA Board,; Shriners Myelo Clinic Nurse and Lifetime Achievement Award winner Elli Meeropol; MSBA Treasurer and Award Winner Brendan Sullivan; SBAA Board Chair Doug Sorocco.

KIDS CAMP 2005!

Pictured here are scenes from Kids!Camp at Conference. Clockwise from top left: During Kids!Camp, a drawing was held, and this lucky girl (Grace Reichenbach of Fort Wayne, IN) won a handcycle! • Grace grins about her new bike. • Kids and counsellors in the room for kids aged 4-6. • Kids and counsellors in the room for kids aged 7-12.

MSBA Members at the SBAA Awards Luncheon

Grace and Andrew living it up in the pool!

Keep an eye out for more conference pictures throughout this newsletter!

AMERICA ANNUAL CONFERENCE 2005***

ON THE ROAD, AGAIN?

BY TRACY CRAVEN

Who says we would not go to any length to meet other families, and find the latest information in medical updates? How about traveling twenty-eight hours in a camper with two teenage children, two dogs, and one big child? YES!

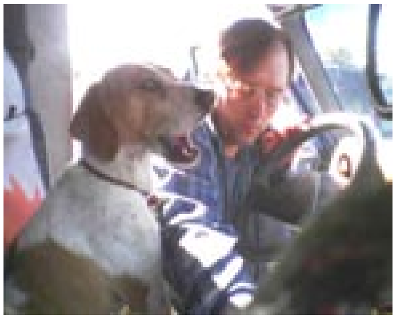
Our family includes myself, my husband and our two kids; Andrew, who will be 18 in October and who has spina bifida, and Danielle who is 15 going on 40.


Andrew, taking a break.

After much negotiation we decided to take our trailer to Minneapolis for the Conference. We were able to attend with help from the MSBA Conference Benefits Program to pay for our Registration Fees. We left at midnight on Thursday and arrived in Minneapolis Monday morning, just three hours before the first Conference session started. Was it worth it? YES. Were we exhuasted? YES.

Andrew is about to turn 18, and after running the gamut of filing for gaurdianship, we needed to get information on SSI as well as dealing with the mental health side of him dealing with his disability. In addition, the sibling group was ideal for our 15-year-old daughter. It was great to have her meet and hang out with other teens her age. The trip also gave us all an excuse for spending time together as a family!

My husband and I divided up the conference sessions, and were able to attend twice as many as we would have by attending each one together. After attending Dr. Steve Sloan's session on sex and the person with spina bifida, I feel much more informed, and had a lot of laughs. For instance, I now know that when you expel gas, and you light it, the flame will be blue! It was also great to get some ideas about how to seriously talk about a rather uncomfortable topic with your teen. We attended sessions on SSI, IEPs, the latest medical breakthroughs in bowel and bladder treatment, and visited booths of many conference exhibitors. At one, we found some of the latest technology in self-contained catheters, which we never knew exsisted.



Other than trying to navigate the one-way streets of Minneapolis from our camp site, attending Conference was a positive experience for the whole family. We are only sad we missed the first day and that we were too exhausted to network more with the other parents. The kids had a great time, and had a vacation away from us at the Kids Camp, (though we were told repeatedly "WE AREN'T KIDS!".

After the conference we drove to South Dakota, and made some memories that will last a life time. We visited Mt. Rushmore and the Crazy Horse Monument. Andrew also wanted to see Little Big Horn, but sadly, we didn't have time to go to Montana. He loves history, and Native American Culture, so, we reached a compromise, and instead of Little Big Horn, visited mustangs at the Black Hills Wild Horse Sanctuary. Both kids love animals, and since Danielle wants to be a veterinarian and specialize in equestrian medicine, let us just say we racked up the points with that one!!!


Teenaged siblings of kids with s.b. had a great time at this year's conferece!

Overall, the Craven family's trip to Conference was great. If you did not or could not attend, I recommend that you order audio tapes of the sessions. That's what we did for the few sessions we missed.

If you have someone in your family with spina bifida — even with all our busy lives, this is the time to take your family to conference. You'll learn huge amounts and have fun doing it! Atlanta next year could be even bigger and better than Minneapolis was this year!

I'd like to take this opportunity to thank the SBAA and all the presenters for everyone's hard work, and also the MSBA for funding our Conference Registration Fees through their Benefits Program.

See you next year when we'll be on the road again to ATLANTA!

MSBA GOLF TOURNAMENT

YES! Our first golf tournament was a success, so we are pleased to announce that we will be hosting our second tournament next year on May 8, 2006!

We raised $3,000 this year. After the fabulous success of Team MSBA in the Boston Marathon, this amount seems small, but it is an excellent start for our first year. Now that we have the experience of our first tournament under out belts, we will be bigger and better next year. To do that successfully, we need your help!

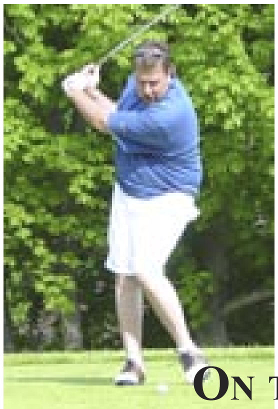
Here are some specifics of what we need:

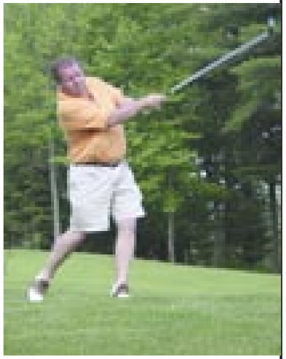
- Volunteers to help with planning
- Volunteers on the day of the tournament
- Leads for sponsors
- Leads for players
- Auction Items (from event tickets to 4 hours of yard work to sports memorabilia – be creative)

If you are interested in helping out or have any leads or ideas, please contact Hyacinth at 978-649-8724 or hbellerose@pblawoffices.com .

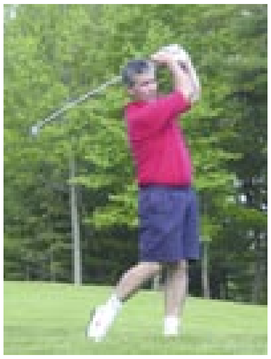
Thank you to all of our supporters this year! We had a perfect golf day, an incredible view at the golf course, lots of fun, and it was all for a great cause. Let's do it again next year!

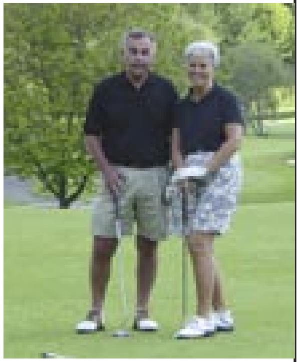
LUNCH!





ON THE COURSE





THE 2006 MASSACHUSETTS SPINA BIFIDA ASSOCIATION 2ND ANNUAL GOLF TOURNAMENT (AND LIMITED AUCTION)

WILL BE HELD MAY 8, 2006 STARTING AT 1:30 P.M AT THE SKY MEADOW COUNTRY CLUB, NASHUA, NH WWW.SKYMEADOW.COM .

AWARDS AND DINNER

FUN IN THE SUN
THE MSBA ANNUAL SUMMER PICNIC

Ice cream, sand art, spray park, fun, and laughter were all part of our MSBA Summer Picnic on July 23 at Danehey Park in Cambridge. The picture perfect afternoon gave 75 of our members a chance to meet new friends, catch up with old friends and enjoy the beautiful weather together.

Many of the children, and a few adults, ventured into the spray fountain to cool off in the beautiful sunshine. Just about all of us also cooled off by eating the delicious ice cream, donated by Ben & Jerry's and drinking bottles of water donated by Roche Brothers Supermarkets. Lunch included giant sandwiches from Subway, who donated plates, napkins and utensils for the event. Thanks to all three companies, as well as all the MSBA members who helped to organize these goodies!

Members of our Youth and Adults Group mingled with new members and their babies, while kids climbed around on the park's huge play structure, played catch, and took turns riding on handcycles. Everyone enjoyed the beautiful sand art created by our youngsters under the watch of Lauren Nordahl. It was a joy to see the delight on their faces as they circled around and around the table, filling their bottles with layers of brightly-colored sand.

By far, though, the best part of the afternoon was seeing our community banding together to have fun and share our care and concern for each other. Thank you to each of you who turned out and made the picnic such a fun event. We hope to see you all again at our Holiday Party in December!









MSBA YOUTH & ADULTS GROUP

MSBAYA FOCUS: NOAH PARSONS

My Name is Noah Parsons and I am the son of Mahlon and Candice Parsons of Sheffield, a small town in rural Western Massachusetts. Although I was home schooled through the 8th grade, I played the trumpet and played piano as well.

In addition to my involvement in music, I became a participant in the local 4-H program. Until my senior year of high school, I raised sheep and grew vegetables and flowers and exhibited all of them at fairs throughout western Massachusetts, including the Eastern States Exposition.

As a 4-H youth, I conducted visual presentations to educate the public on agricultural, environmental and health topics. Five years ago I began selling vegetables and cut flowers from my front lawn. For my business venture I received the Young Entrepreneur of the Year award given by the National Foundation of Teaching Entrepreneurship.

As a person with spina bifida (L3-L4), I began looking for opportunities to meet other people with disabilities during high school. There are very few opportunities in the area where I live and my social interactions were limited to my role as manager of my high school's boys' cross country and track and field teams. At the conclusion of my freshman year, I joined a youth group of teenagers with disabilities in Springfield, MA. This program is called Making Healthy Connections, and is funded through the organization Partners for Youth with Disabilities.

For two years I met with the group and developed relationships with both the staff and youth before I became a peer leader. As a peer leader I was responsible for greeting new members and acting as an intermediary between the adult staff and the teenage members. This summer I hope to continue my relationship with PYD and become an adult mentor. In the fall, I will actively pursue establishing an adaptive sports program at the University of Michigan, where I am a student of Near Eastern studies and Russian and Eastern European studies.

The sum of my life's experiences have taught me the value of self-advocacy and a willingness to persevere in adverse situations. One particular example of this is my college application process. The services I received to help me prepare for college were insufficient, but I applied to five respectable universities and colleges just the same, and the University of Michigan accepted me as one of its students.

Spina bifida is my most visible disability, but I was also born with hydrocephalus, which was the source of my learning disabilities. The staff from my school, my parents and I created an IEP to provide me with the necessary accommodations and services. My IEP stated that I would work with my guidance counselor in preparing my college applications and interviews. I met with my guidance counselor every week as the IEP outlined. My guidance counselor proceeded to divide my list of schools into three categories and added other schools to supplement the list. These categories included: 1) high probability of acceptance, 2) reasonable probability of acceptance, and 3) very low probability of acceptance. All the schools on my own list, except one (SUNY-Binghamton), fell into the third category. Although my guidance counselor's predictions were depressing, I felt certain that I could be a student at one of my choices, and ultimately succeeded in this goal. I am grateful for the support and encouragement of my parents and Arabic tutor during that stressful time.

As a student with spina bifida on a college campus, one of my largest concerns is mobility. On an average day at home I would walk around all day with my floor reaction braces. However, the buildings on campus that I need to access are much farther apart than those at home. In the first semester, I was exclusively in a wheelchair to get to my classes and other events and also used a para-transit van service. Several times the van did not show up and so I went to class in the wheelchair. In the second semester, I used the wheelchair for long distances and walked to the classes located closest to my dormitory. For the majority of football game days, my scheduled rides did not arrive on time and I used the wheelchair.

Since a young age, I've had high expectations of what I ought to achieve and I have always tried to find different methods for meeting my expectations. As a person with spina bifida, I feel that it is necessary to have a clear vision of one's goals in order to reach them and set a standard with no limits.

The Summer heat has not slowed down the MSBAYA Planning Committee. Below is a list of upcoming events. Watch your mailboxes, the MSBAYA Yahoo Group and the MSBA web site (www.msbaweb.org) for more information. You do not want to miss out!

UPCOMING MSBAYA EVENTS

• Saturday, August 13, 2005	Bowling (12:30 pm - 3:00 pm)	Lanes & Games, Cambridge, MA
• Saturday, September 24, 2005	Sports Clinic (1:00 pm - 4:00 pm)	MA Hospital School, Canton
• Sunday November 6, 2005	Activity, TBD	Location, TBD



MSBA YOUTH & ADULTS GROUP COMMITTEE

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

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

MSBAYA Members enjoyed sunshine and good times at recent events: The SBAA Annual Conference in Minneapolis, MN; The 1st Annual MSBA Golf Tournament in Nashua, NH; and at the MSBA Annual Summer Picnic in Cambridge, MA.




APPLICATIONS ARE NOW BEING ACCEPTED TO JOIN THE MSBAYA PLANNING COMMITTEE

The MSBAYA Planning Committee needs your help! With the recent growth in MSBAYA membership and participation, the MSBAYA Planning Committee is looking for volunteers to assist with activities, including coordination of events, transportation, flyer preparation, and moderating its online Yahoo!Group. Planning Committee meetings are held every other month at the Burlington Mall in the Food Court. If you are interested in participating (you do not have to have spina bifida to volunteer your time), please email a paragraph or two about yourself and why you would like to volunteer to Jen Kuhar at jenkuhar@msn.com, or via postal mail to the MSBA at:

MSBAYA Planning Committee
Massachusetts Spina Bifida Association
733 Turnpike Street, #282
North Andover, MA 01845

MSBA MEMBERSHIP INFORMATION

The Massachusetts Spina Bifida Association is a nonprofit corporation founded in 1971 by a group of concerned parents of children with spina bifida. A member of the Spina Bifida Association of America, the MSBA is dedicated to enhancing the lives of people in Massachusetts affected by spina bifida by providing a community of support, advocacy and education.

- A few of the benefits members enjoy include meetings, a strong Youth and Adults Group, fundraising, an extensive Benefits Program, social events, a developing Parents Helping Parents program, a Parents' Chat Group, online discussion groups, and a lending library.
- The MSBA Board is open to suggestions from members as to how we can better serve our community. Please watch this newsletter and our web site at www.msbaweb.org for ongoing events and programs.
- "Qualified Members" of the Association receive the MSBA's quarterly newsletter, the SBAA's newsletter *Insights*, and may receive other MSBA benefits.
- There is no membership fee, but tax deductible donations are appreciated. ***To become a member,*** either ***visit our web site and fill out the online form*** or ***fill out the application on the next page***, and return it to:

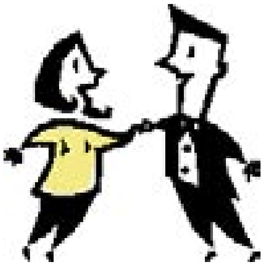
MSBA Membership, 733 Turnpike Street, #282, North Andover, MA 01845 .

- **Who is a "Qualified Member"?** A person with Spina Bifida who resides in Massachusetts or a New England state that does not have its own SBAA affiliated entity. (See page 12 for more details.)
- Please send us an update whenever there are any changes to your information, including your email address!
- Members can also update their information by sending an email to mattneal@alum.mit.edu .

FUNDRAISER TO BENEFIT THE MSBA

WHAT? SPINA BIFIDA RESEARCH FUNDRAISER
HOSTED BY THE FOTI FAMILY,
WITH PROCEEDS TO BENEFIT
CHILDREN'S HOSPITAL BOSTON
AND
THE MASSACHUSETTS SPINA BIFIDA ASSOCIATION.
INCLUDES DINNER, DANCING, AND CASH BAR,
AS WELL AS RAFFLES AND DOOR PRIZES.

DATE: NOVEMBER 5, 2005
LOCATION: DANVERSPORT YACHT CLUB
TIME: 6:00PM
COST: $55.00 PER PERSON



TO ORDER TICKETS, CALL ROSALIE FOTI AT: 978-283-6447

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 info helps us provide appropriate support to members of different ages): ____________
Spouse / Partner / Other Family Members : ____

Member Name (if different from person with s.b.): ____________________________
Organization and Title (if appropriate): _______________________________________
Street Address: ____
City, State, Zip: ____
Telephone: ____________________ **Email**: _________________________________

Please contact me about becoming a volunteer ___

Optional tax deductible donation $____________

Other information you would like us to know (siblings, level of sb lesion, suggestions, etc...):

____
____
____
____
____
____

Please tear out this application form and return it to:

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

MSBA BENEFITS PROGRAM

QUALIFIED MEMBERS*

OF THE MSBA ARE ELIGIBLE FOR SIGNIFICANT FINANCIAL HELP EACH YEAR THROUGH OUR BENEFITS PROGRAMS! SEE BELOW FOR DETAILS.

WHAT IS A "QUALIFIED MEMBER"?

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

ANNUAL BENEFITS PROGRAM

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

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

2006 SPECIAL CONFERENCE PROVISIONS

The MSBA Board of Directors is currently reviewing the specifics of the Benefits to be offered toward next summer's SBAA Annual Conference, to be held in Atlanta, GA, June 25-29, 2006. Please watch this space in the Fall edition of the MSBA News for full details and how to apply.

Requests outside of this scope will be reviewed on an individual basis.
Benefits Program payments can take up to 30 days to process.
The MSBA reserves the right to revise this policy in accordance with the changing financial position of the MSBA.

** Please note: Membership in the MSBA is not required to receive Benefits.*

MSBA BENEFITS FORM

Name: ______________________________

Street Address: ______________________________

City, State, Zip: ______________________________

Telephone: ____________________ **Email**: ____________________

I AM APPLYING FOR:

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

___ Receipts Attached

___ Make check payable to enclosed provider

→ ____________ GRAND TOTAL REQUESTED

Below, please include an explanation of the benefit you are requesting and what it will be used for. Attach extra pages, if necessary. No particular format is required.

____

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Please tear out this application form and return it to:

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

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 becoming more involved or have any issues or concerns to be brought up at a meeting, please contact any one of us.

- The Board solidified the MSBA Strategic Plan. To view a copy of the document, please visit the MSBA web site at www.msbaweb.org . Details of a committee structure based on the Strategic Plan are listed in this newsletter and on the web site.
- The First Annual MSBA Golf Tournament raised approximately $3,000 for the MSBA. The 2006 Golf Tournament will be held on Thursday, May 8th at 1:30 at Sky Meadow Country Club in Nashua, New Hampshire.
- Cori Couture is designing a label for the MSBA canister program, which Jen Kuhar will be managing.
- The Board unanimously voted Erin Murphy as the 2005 Jean Driscoll Scholarship recipient. Erin was given her award of $1,000 at the MSBA Picnic on July 23, 2005.
- The MSBA is currently looking into hiring a staff member and obtaining office space and will form a Hiring Committee.
- The MSBA has formed a Finance Committee, which plans to begin meeting in the near future. Committee members are Brendan Sullivan, Michael Sullivan, Tom Sileo, Marc Bellerose, and Jen Kuhar. Their first task will be to devise a Business and Finance Policy Statement for our organization.
- Our Treasurer, Brendan Sullivan submitted his resignation from the MSBA Board, to be effective at the MSBA Annual Meeting in October. We will all be very sad to see him go!
- The MSBA plans to hold a travel preparedness workshop prior to the 2006 SBAA Conference.

WHO'S OUT THERE?

(MSBA MEMBER SPOTLIGHT)

THIS MONTH'S FEATURED MEMBERS: AMY BLANCHARD

BLOGGING ABOUT BEING A MOM WITH S.B.

My name is Amy Blanchard. I am a 31-year old woman living with spina bifida. I wear short leg braces and use a walking stick to help me with mobility. I currently live in Wilton, NH with my husband and 2 1/2 year old daughter.

I had a pretty typical childhood. Yes, I had more than my fair share of operations, but those were mostly performed during the summer so as to not keep me out of school for large chunks of time. If I ever did have to have a procedure done during the school year, my school(s) and classmates were always very accommodating and helpful. I had classmates begging me, in fact, to choose them as my helpers for the day to take me in the elevators and assist me in any way they could. In short, I had a very happy childhood experience. I never doubted that I could do anything I wanted. I knew my limits, of course, but I also knew I had an intelligent mind, creative nature, and a very loving and supportive family, all of which have helped me to achieve all that I have today.

My biggest issue with my s.b., I feel, is that, coupled with my quiet personality, I am a very shy person. I do loosen up once I get to know people, but I find it difficult to meet new people and make good friends. Because of this, I always wondered if I'd ever meet a man to fall in love with and whom I would want to marry. I didn't date very much in high school or college and I'm not one to go out to clubs or whatnot, so I didn't know how I'd find him.

Cut to my first day on the job at the company I still work for, some eight years ago. As my then boss took me around on a company tour, I met a lot of people – including the man I would later marry. I started work on a Tuesday; that Friday he invited me out to a company function in the evening. We've been together ever since. He's a handsome, healthy, able-bodied man who loves me for who I am and what I can teach him about patience, determination and strength. I love him for believing in me, for helping me to accomplish my life's goals, and just for being the intelligent, multi-faceted, artistic man that he is. We married on a beautiful, New England autumn day after a two and 1/2 year courtship.

We always knew we wanted children. We talked about what we would name our kids and what values we would like to instill in them as they grew. It wasn't until we were married for a couple of years, though, that we seriously began the process of starting a family. We had a lot to think about – would I be able to handle the weight gain and bodily stresses of a pregnancy or would I have to use a wheelchair for the last trimester or so? Would I be able to detect labor and/or deliver vaginally or would I have to schedule a C-section? What was the probability of passing on s.b., or any disability, to our unborn child? What special lifestyle changes could I make to increase the chances of having a healthy pregnancy and baby? What medical tests should I have done and what medical specialists should I see to help me through a pregnancy? These and many other questions ran through both my own and my husband's minds.

We started on our journey to parenthood by first trying to research all our questions and meeting with my OB/GYN, neurologist and chiropractor. The doctors gave us some information and their best medical opinions of what pregnancy and childrearing would be like for me, but none of them could tell us with any certainty how my body would react. They all encouraged us to go forward with our plans, though, and they promised to work with me to make sure my experience was as healthy, happy and normal as possible.

The research I did online and in bookstores, however, came up empty-handed. I just could not find anything of use that told me about the experience of being a pregnant woman with s.b. I found a ton of information about having children with spina bifida, but hardly anything at all about the parent having the disability. I did find a few web sites and on-line networks for disabled parents in general, but nothing at these sites seemed to fit me personally or give me any useful information for my specific case. This extreme lack of information frustrated both my husband and me very much and I personally vowed right then that I would change this in the future for women with spina bifida who wanted to become mothers.

Needless to say, my husband and I did go through with our plan to have a baby. My pregnancy went very smoothly and I was able to walk, as normal, the entire time. I kept up with my doctor appointments, tests and ultrasounds. It was at one of these ultrasounds that we found out that our baby girl had a beautiful, healthy spine – along with everything else. Labor and delivery were quick and relatively easy. I had wonderful doctors all along the way and supportive family and friends. And now, our healthy daughter is 2 1/2 years old, very active, very smart and very adorable. We couldn't be happier.

About 2 months ago I started to make good on my promise to make a difference in the lives of other women with spina bifida who want to have children. I established a blog – an on-line journal, or web log - in which I recall my experiences with pregnancy, labor and delivery, and I record the daily experiences I have as a disabled mother raising a healthy, active toddler. I'm having a blast writing my story and I am thrilled to get the occasional email and/or comment from readers interested in what I have to say. I am not a medical professional, I only have my story to share. But if my one story can inspire the life of just one person with spina bifida to achieve her dreams of parenthood, then I have made a difference and done my part. I absolutely love being a mother and encourage anyone who wishes children into their lives to see that wish come true. You just have to look forward with both eyes open and be receptive to whatever the future holds for you.

You can visit my blog, called "Spina Bifida Moms" at http://spinabifidamoms.blogspot.com . I post a new entry every Sunday afternoon – more often if time permits and/or inspiration hits. Please don't be shy about commenting or contacting me – I love to hear from my readers, encouraging and helping you in any way that I can. Thanks for reading… Please visit soon!

APPLICATIONS ARE NOW BEING ACCEPTED FOR THE MSBA BOARD OF DIRECTORS

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

Finance
Public Relations
Fundraising
Medical Fields / Health Care
Social Work

Please send inquiries to:

Prospective New Board Members
Massachusetts Spina Bifida Association
733 Turnpike Street, #282
North Andover, MA 01845

ADULT HEALTH CARE GUIDES

THE SBAA HAS PROVIDED THE MSBA WITH HEALTH CARE GUIDES FOR ADULTS WITH SPINA BIFIDA. WE HAVE A LIMITED NUMBER OF COPIES ON CD-ROM OR PRINTED, IN 3-RING BINDERS.

IF YOU WOULD LIKE ONE, PLEASE LEAVE A MESSAGE ON THE MSBA'S VOICE MAIL SYSTEM (888-479-1900).

THE 2005 JEAN DRISCOLL SCHOLARSHIP

In 2002, when the MSBA was applying to become an official charity of the Boston Marathon, one of our greatest promoters and sources of support was Jean Driscoll. An adult with spina bifida, Jean holds the record for winning the Boston Marathon more times than any other individual. She reached the finish line ahead of her competitors a total of eight times, in the wheelchair division of the race. During the lead up to Team MSBA's first year in the Marathon, Jean came to Boston to tell the story of her efforts. A wonderful motivational speaker and a genuinely kind person, she made everyone in the room feel like they could do anything. In thanks for the help and encouragement she offered both to our Marathon Team and to the members of the MSBA, the Board established an annual scholarship in her name. The Certificate given to the person who wins the award each year reads as follows:

"In appreciation for her support, inspiration and dedication to the spina bifida community in Massachusetts, the Board of Directors and members of the Massachusetts Spina Bifida Association created the Jean Driscoll Scholarship. Presented annually, this $1,000 award is to be used by the recipient for educational, athletic, developmental or assistive programs." Through this award, we honor "the individual with spina bifida in Massachusetts who best demonstrates the character and determination of the scholarship's namesake."

The Board reviewed a number of very impressive applications for this year's scholarship, and it was hard to choose just one recipient. Our thanks and best wishes go out to all who applied. In the end, we selected Erin Murphy.

THIS YEAR'S RECIPIENT: ERIN MURPHY

Erin Murphy is an adult with spina bifida, who lives in Cambridge, MA. She holds a BA in Psychology from Boston University and is currently employed with the Child-At-Risk Hotline, an after-hours emergency service for the Department of Social Services in Massachusetts. At the Hotline, Erin works as a screener, taking child abuse and neglect reports, and also works as the Hotline's administrative associate. In her spare time, she is a literacy tutor at the Cambridge Public Library.

Through her experiences in both of these jobs, Erin realized that she has a strong interest in helping people, and decided to apply to the Clinical Social Work program at Boston University. She was accepted into the program, and, partially thanks to the Jean Driscoll Scholarship, she will begin attending classes in the fall.

One of the recommendation letters that came with Erin's scholarship application described her as someone who has "...faced many challenges in her life and has been focused and ultimately successful in finding solutions to everything that life has thrown her way. She has dealt with everything from a learning disabilty to finding accessible housing in Boston's limited residential market. She has taken the prejudices she has faced in society, such as from metro transit employees, and stood up not only for herself, but for others who face similar discrimination. Erin has taken all the things she has learned from living with spina bifida and utilized that knowledge to focus on living her life completely and to her fullest potential."

Many of us met Erin at the MSBA Picnic, and were struck by her ready smile and positive energy. Congratulations, Erin and good luck at BU this fall!

ACCESSIBLE RECREATION PROGRAMS OFFERED THROUGHOUT MASSACHUSETTS

dcr | *department of* Conservation and Recreation

The Division of State Parks and Recreation's Universal Access Program is dedicated to providing outdoor recreation opportunities in Massachusetts State Parks for visitors of all abilities. Accessibility to our State Parks is achieved through site improvements, specialized adaptive recreation equipment, and accessible recreation programs. To discover parks and forests that offer accessible recreation opportunities, see the partial list below, or visit the DCR's Universal Access web site (http://www.mass.gov/dcr/universal_access/) for more information. You can also contact the Universal Access Program office at P.O. Box 484, Amherst, MA 01004. Or call 413-545-5353 voice; 413-577-2200 TTY.

Notes from Tom McCarthy, Universal Access Program Director

The State Parks for Everyone project, funded by the U.S. Department of Education and the the Department of Conservation and Recreation, came to a close this June. Over the past three years, SPE sought to expand the state-wide Universal Access recreation program to increase the number of persons with disabilities participating in outdoor recreation activities in integrated State Park settings. This successful program has helped increase the number of established accessible activities as well as adding new programs, such as horseback riding and snowmobiling. Over 1,000 individuals with disabilities have participated in these programs, many on a regular basis. The work begun by SPE will continue in our parks thanks to the ongoing support of the Department and the friends and partners we have made through this effort.

In the coming year, we look forward to continuing our work with other New England states as part of ***Project INSPIRE*** to disseminate and highlight details of the work that has been done in the Massachusetts Department of Conservation and Recreation to successfully open the natural world to everyone.

This summer we will continue to offer our popular paddling programs across the state. This year there will be a $3.00 per person fee that will help cover a small portion of the cost of these programs. As the popularity of these programs grows and expenses increase, we are always looking for ways to help us to continue our work without decreasing the quality of the experience. I'm looking forward to seeing many familiar and many new faces at all of our programs this summer and fall.

Universal Access Program 2005 Summer/Fall Activities

Pre-Registration Contact Information

Cycling program: *All Out Adventures* and *Adaptive Sports and Recreation* - Call: 413-527-8980.

Paddling programs: *All Out Adventures* - Call: 413-527-8980 (All programs except Hopkinton)
Hopkinton Program - *Outdoor Recreation of Hopkinton* – Call: 508-435-3965

Rowing program: *Holyoke Rows* - **CALL 413-586-8612**

Accessible Hiking Program: Join *Venture Into Well-Being* on the trail in state parks around Massachusetts! Assistive equipment and teamwork help people of all abilities access conventional hiking trails at a leisurely pace. Adaptive equipment includes Terra Trek manual wheelchairs, baby joggers, walkers, crutches and gait belts. These free programs often include nature interpretation and other fun-filled components. For more info and to register, call 413-259-0009. Program may be extended into fall.

✯NEW Program! Orienteering!✯ Come discover a whole new way to enjoy the outdoors! Learn how to read maps and use a compass to find your way in the woods or even in town! This program will teach orienteering skills and how to locate and access letterboxes – a unique passport system in the outdoors – with an emphasis on accessibility. Wheelchair accessible trails are used to make this activity as independent as possible. Sign up in advance by calling Bryce Fifield at All Out Adventures at 413-527-8980 to participate.

Paddling on the Connecticut River Join *All Out Adventures* for day or evening paddling on the Connecticut River! Costs for these explorations are: $25 per person for a day paddle with a $50 cap for families, $15 if you bring your own boat(s) and $5 per person for an evening paddle. To pre-register, call 413-527-8980. A Project INSPIRE Program.

For More Details on all accessible programs offered by the DCR, visit their web site: http://www.mass.gov/dcr/universal_access/

BITS AND PIECES

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

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

BY HYACINTH BELLEROSE

- **DAVIS FARMLAND:** www.davisfarmland.com GREAT ACCESSIBLE SPRAYPARK; also has playground, zoo, clean accessible restrooms, allows you to bring your own food, and more. For my 10 year old (with s.b.) and my 4 year old, this was definitely worth the price and the drive. Check it out for a hot day!
- **CRAIG'S LIST:** www.craigslist.com Click on the "Boston" or "New Hampshire" area of the site and start exploring. New Hampshire is just developing and both areas of the site have some overlap. This site offers an easy way to give away, sell, buy or get "Free Stuff". Among hundreds of other categories, there are events and job listings. (I just hired a new assistant from placing an ad on Craig's list and she is great!) It's worth a look to see if Craig's List could be a useful tool for your household.
- **HAND IN HAND CHILDREN'S CENTER:** Finally – Daycare which includes children that have special needs! At 462 Walpole Street, Norwood, MA Tel: 781-702-6591, Hand in Hand Children's Center is a flexible day care provider that is fully accessible, has a pediatric nurse on staff and assists with the medical needs of the children. Other than reviewing the flyer, I have had no contact with this Center, but the idea is excellent. No more "we cannot accept your child still in diapers"!! If anyone checks this out, please let us know your impression.
- **FAMILY TIES OF MASSACHUSETTS:** is a statewide information and parent-to-parent support project for families of children with special needs and chronic illness. For a FREE copy of the Family TIES 2005 Resource Directory, either download or request it from http://www.massfamilyties.org/ or call Kathy Morin at 978-851-7261 x4018. The directory is a wonderful resource. While on the web site, also check out the link to the...
- **FEDERATION FOR CHILDREN WITH SPECIAL NEEDS:** (www.fcsn.org). They may be having a useful program at your local school. This web site is also in Spanish.

TRANSITION: IN THE WORLD OF SPECIAL NEEDS, TRANSITION IS A VERY MEANINGFUL WORD. IF YOU OR A FAMILY MEMBER IS GETTING TO THE AGE OF TRANSITION OUT OF THE SCHOOL SYSTEM, YOU MAY WANT TO CHECK OUT THE FOLLOWING FOR SOME HELPFUL TOOLS, INFORMATION AND RESOURCES.

- **ADOLESCENT HEALTH TRANSITION PROJECT:** (http://depts.washington.edu/healthtr/) The web site for this program provides transitioning resources, tools and information for youth, families and health care providers.
- **AMERICAN ACADEMY OF PEDIATRICS - NATIONAL CENTER FOR MEDICAL HOME INITIATIVES FOR CHILDREN WITH SPECIAL NEEDS:** (http://www.medicalhomeinfo.org/) Web site includes tools to support transitioning of youth with special needs as well as a training module on transitioning that is a part of the "Medical Home" curriculum.
- **HEALTHY AND READY TO WORK:** Provides web-based tools, resources and strategies that can be used by youth and their families, health care providers, and state and local agencies to achieve successful transition from pediatric to adult health care. Visit: http://www.hrtw.org/.
- **INSTITUTE FOR CHILD HEALTH POLICY - PROMISING PRACTICES IN HEALTH CARE TRANSITIONS PROJECT:** (http://hctransitions.ichp.edu/) includes multiple transition resources, including tools that can be used to support transitioning, an annotated bibliography of transition references, transition training materials, links to projects related to health care transitions and a transitions listsserv.
- **INSTITUTE ON COMMUNITY INTEGRATION:** Works with community service providers, school districts, advocacy organizations, policymakers and researchers to provide information and practices that support the community integration of individuals with disabilities. Visit their web site at: http://ici.umn.edu/ .

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
• August 13, 2005	**MSBAYA Bowling Event** (12:30 pm -3:00 pm)	Lanes & Games, Cambridge, MA
• September 12, 2005	MSBA Board Meeting (7:00 pm)	Centres at Burlington
• September 24, 2005	**MSBAYA Sports Clinic Day** (1:00 pm - 4:00 pm)	MA Hospital School, Canton
• October 3, 2005	MSBA Board Meeting (**Annual Meeting**) (7:00pm)	Centres at Burlington
• November 5, 2005	Foti Family **Dinner/Dance Benefit** (6:00 pm)	Danversport Yacht Club
• November 6, 2005	**MSBAYA Event**	Details TBD
• November 7, 2005	MSBA Board Meeting (7:00pm)	Centres at Burlington
• December 5, 2005	MSBA Board Meeting (7:00pm)	Centres at Burlington

For the most up-to-date info on MSBA events and info, visit our web site (www.msbaweb.org) and sign up for ou online discussion groups: msbaya@yahoogroups.com and msbaparents@yahoogroups.com .

SPECIAL CONTRIBUTIONS

- Karen and Hannah Coomber made a special donation “in honor of two wonderful Kindergarten teachers in Auburn, MA; Mrs. Sheila Clifford and Mrs. Debra Nordberg. Because of their efforts, Hannah had a wonderful year.”
- Special thanks to Christina and Joseph Scaramozza, for generously donating to the MSBA the $90 they raised during a yard sale at their home in Melrose in May.
- Thanks to the Children’s Hospital Orthopaedic Surgery Foundation for their annual donation of $500 to the MSBA. We promise it will be put to good use!

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

Phone: 888-479-1900

Web Site: www.msbaweb.org

Fall Newsletter Deadline

September 30, 2005

PLEASE SUBMIT ARTICLES AND INFORMATION FOR PUBLICATION TO:

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

UPDATE YOUR MEMBERSHIP TODAY!

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

(SEE PAGES 10-11 FOR DETAILS)

Newsletter Editor: Cori Couture

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

Note: The information in this newsletter is provided solely for informational purposes. It is not intended to be, nor is it, medical advice on the management or care of a person with spina bifida. Although every effort is made to assure that information is accurate and current, knowledge in the field of spina bifida is growing rapidly and all data are subject to change without notice. Neither the MSBA nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The MSBA does not endorse any specific medical regimen. You should not change your medical schedule or activities based on the information provided in this publication. Always consult with a doctor, health care provider, or other medical professional before making any medical decisions. MSBA does not employ medical personnel in its organization.