MSBA NEWS

A PUBLICATION OF THE
MASSACHUSETTS SPINA BIFIDA ASSOCIATION

MEMBER, SPINA BIFIDA ASSOCIATION OF AMERICA

- WINTER 2005 -

Santa prepares to hand out presents during the 2004 MSBA Holiday Party held Decmeber 4th at Boston College. See page 3 for more photos & a full party recap!

LETTER FROM THE PRESIDENT

BY BRIAN PACKARD

Happy 2005 to you all.

I hope this newsletter finds you enjoying health and happiness in this New Year. With the holidays behind us, we can all now turn our attention to what will be another great year for the MSBA. At the time of my last note, the Sox were on their way to sweeping the World Series. Who would have thought that just three months later, we'd be on the edge of our seats again, this time cheering on the Pats to claim their third Super Bowl win in four years?!

Many of you were able to join us at our Holiday Party at Boston College on Saturday, December 4th. As always, it was wonderful to gather with all our MSBA friends in celebration of the season. With a turnout of 70+ people, the party was a great success, highlighted by a visit from Santa and a fiercely competitive Yankee Swap! Many thanks to everyone who helped to plan and run the event, especially Jen Kuhar and Jen Fitz-Roy. We'd also like to thank Boston College for providing a perfect location for our annual party. We are already making plans for our next major gathering, the annual Summer Picnic. Please be on the lookout for flyers and notices in our next newsletter, or visit our web site www.msbaweb.org for details on all upcoming events.

The MSBA Youth and Adults Group continues its active agenda, with its next major event, an Open Discussion Day, planned for Saturday, February 19th at Children's Hospital in Boston. Unfortunately, Mother Nature caused the postponement of last month's MSBAYA Lunch and Learn in Sturbridge. With our track record of snow-covered cancellations, we'll be consulting the Farmer's Almanac before scheduling our next event in these brutal New England winters.

We are looking to replicate the success of the MSBA Youth and Adults Group by creating a new online discussion group for the parents in our organization. This forum will allow our parents to share questions and insights on the challenges and joys of raising a child with s.b. Once we get a solid online community going, hopefully we'll be able gather interest for in-person meetings and events for this audience. So, all you parents out there... please see inside this issue (page 16) for more information on the discussion group, and get involved!

Over the last few months, our Board Members have continued to staff an MSBA Information Desk at the Children's

Continued on Page 8

INSIDE THIS ISSUE

MSBA OFFICERS

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

VICE PRESIDENT
Hyacinth Bellerose 978-649-8724
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@fastmail.fm

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
96 Pondview Circle
Brockton, MA 02301
Phone: 508-587-6788
Email: orchid502@yahoo.com

Patricia DeMoranville
334 Main St. Apt. 312B
Fairhaven, MA 02719
Phone: 508-992-1484
Email: pdcv1230@aol.com

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
Email: bniedzwiecki@hotmail.com

NORTH SHORE / MERRIMAC VALLEY
Cindy Ward 978-682-9330
25 Devon Court, North Andover, MA 01845
Email: muna000@aol.com

MSBA TELEPHONE **888-479-1900**
MSBA FAX **978-549-8725**
SBAA TELEPHONE 800-621-3141

COMMITTEE CHAIRPERSONS

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

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

CANISTER COLLECTIONS - VOLUNTEER NEEDED

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

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

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

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

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

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

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

PUBLIC AWARENESS / PUBLICITY - VOLUNTEER NEEDED

YOUTH & ADULTS GROUP
MIchele Scaramozza 339-927-7227
Email: mozzasmsba@comcast.net

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

2004 MSBA HOLIDAY PARTY RECAP

BY GINNY BRIGGS

The 2004 Holiday Party was a smash hit this year. Thankfully, the weather cooperated and we had sunny skies all day. Approximately 75 people gathered at Boston College on December 4th, and spent the afternoon listening to music, playing games, and eating some great food supplied by the BC caterers.

The afternoon started with a delicious buffet of fresh sandwiches, salads, chips, and a wonderful assortment of desserts and candies. Following a filling lunch, continuous announcements were made for a variety of activities designed for both kids and adults. There was a jelly bean counting contest, a mystery gift guessing contest, and a Yankee Swap. There were also countless activities for the kids, including coloring, crafts and a visit from Santa himself! Santa very nicely brought some early Christmas gifts for all the children who came to the party. When he began to feel over-heated in his heavy winter suit, we reluctantly had to let him leave to make that long trip back to the North Pole. We're sure he'll be back next year, though!

The activity most enjoyed by many of the adults seemed to be the Yankee Swap. Each person was given the opportunity to choose a new, wrapped gift or to take one that had already been opened by someone else. For the most part, people kept the gifts they unwrapped, with the exception of one or two very popular items, including a $10 gift certificate to Target. Some 5 different people had their eye on that one!

The MSBA would like to extend its heartfelt thanks to all who participated and who helped to organize this great event – especially Jen Kuhar, Jen Fitz-Roy and the Boston College Disability Council. If you were not able to make this party, be sure to come to one of our next big events. The MSBA Youth and Adults Group has events scheduled for February and April (see page 7). Also, the MSBA hopes to have another great showing at the SBAA's Annual Conference in June and, as usual, we will host a summer picnic at a time and location to be determined. Please watch the next issue of the newsletter for details!

SBAA CONFERENCE 2005

YOU NEED TO ATTEND!

BY HYACINTH BELLEROSE

The Spina Bifida Association of America is holding its annual conference in Minneapolis, MN from Sunday, June 26 to Wednesday, June 29, 2005 and the theme is "**Building Bridges to Advance Understanding**". Bringing the event to a new level this year, the SBAA's Conference will be combined with that of The International Federation for Spina Bifida and Hydrocephalus. This will bring an infusion of people from all over the world and should allow us all to experience some new and different perspectives on living with spina bifida.

This year, an **Adults Day** (on Sunday June 26th) has been added to the mix. Based on a similar event held at the International Federation Conference in Norway last September, the Adults Day will serve as an umbrella event for the discussion and exploration of issues that affect adults with spina bifida. The MSBA is hoping this extra day will allow our adult members to attend as many adult-specific sessions as they like, and still have time to attend sessions on other topics during the rest of the conference.

CONFERENCE CONNECTION – This is the second in a series of articles about the conference. It is an obvious attempt to increase conference participation among our members. The MSBA would like to see as many of you attend as possible and would like to make the conference experience as fulfilling for everyone as it can be. In order to do so, we will be having a *Conference Preparation Meeting* in June, so that all our members who are planning to attend can meet each other and make plans for staying in touch during the conference. Each prospective attendee will receive a detailed package including hotel details, information about the city of Minneapolis, and a list of possible activities and sites to visit while there. For example, three **Minnesota Twins baseball games** are scheduled during conference and the most expensive ticket is less than $50! Betty Niedzwiecki has volunteered to organize an outing to one of the games. If you are interested in attending, please contact her and let her know whether you need accessible seating. Betty can be reached at 413-774-3489 or bniedzwiecki@hotmail.com. Thanks Betty!

CONFERENCE FUNDING – Remember that the MSBA Benefits Program can provide substantial help (up to $1,250) toward financing your trip to conference (see pp. 12-13 for details). Meanwhile, watch this newsletter, our web site www.msbaweb.org, and the SBAA's newsletter *Insights* for information on additional funding sources. If you are willing to follow MSBA requirements for the full conference benefit and tap into one or two other sources, you should be able to attend the conference and really enjoy the city. One of our Board members has written letters to local businesses to see if she can obtain funding for her trip. We will let you know how it goes. In the meantime, you can try the same experiment yourself. Go to www.sbaa.org, click on "Conference Funding Tips" and draft your own letter to send to the local divisions of the organizations listed. Word is that a lot of adults with s.b. from around the country have been exploring this idea of asking for funding from local businesses and they've had good responses so far. It never hurts to ask!

AIRLINE – Northwest Airlines is the only airline that flies directly from Boston to Minneapolis. If you plan on flying to conference, you may want to make reservations early, so that you *can* fly direct. At this point, the best deal I found on Northwest was from June 25th to June 30th for $346.90. Northwest Airlines provides a lot of helpful information on their web site about accessibility. The web address is: http://www.nwa.com/services/onboard/special/.

Also, The U.S. Department of Transportation's toll-free hotline for Accessible Air Travel for People with Disabilities is 1-800-778-4838.

An airport taxi service for people with disabilities is located between Doors 3 and 5 at the Baggage Claim Level of the Minneapolis airport and should cost about $25 to get you to the hotel.

You can also make reservations for the airport shuttle at www.supershuttle.com (1-800-bluevan) or go to the MP SuperShuttle counter at the airport ($13 each way; $2 off return if purchased at same time).

HOTEL ROOMING – The SBAA rate for rooms at the conference hotel is $125 plus tax per night. If you are planning to attend the conference, would like to share the cost of a room with someone, and do not have a candidate in mind, please provide a member of the Board with your name and contact information. We will make a list of all MSBAers attending, and try to match people with potential roommates. By providing us with your name, you will be giving the MSBA Board permission to include your name on the list of people attending.

25TH NATIONAL VETERANS WHEELCHAIR GAMES June 27 - July 1, 2005 at the Minneapolis Convention Center. Over 600 veterans in wheelchairs will be competing for gold, silver and bronze medals at the Minneapolis Convention Center and throughout the Twin Cities area. Events include Track & Field, Swimming, Basketball, Weightlifting, Softball, Air Guns, Quad Rugby, Bowling, 10K Hand Cycling, Archery, 9-Ball, Table Tennis, Slalom, and more. For details on this and other events, visit the Convention Center web site: http://www.minneapolis.org/ .

ACCESS PRESS – Check out Minnesota's Disability Access Newsletter at www.accesspress.org or call 1-651-644-2133 to find out about subscribing for the next few issues.

Finally, feel free to let us know if there are any resources you need the MSBA to check into prior to the conference. Think of any information you *wish you had known* from other conferences. You can call me at 978-649-8724 or send me an email at: bellerose33@charter.net.

A SALUTE TO EXTRAORDINARY COMMITMENT

THREE-TIME TEAM MSBA RUNNER JANELLE TRIBBLE GOES THE EXTRA MILE FOR THE CAUSE

BY BRIAN PACKARD

Late in the fall of 2001, I got a call from a Boston College student "dying to run the Boston Marathon for a good cause." On the line was Malden native Janelle Tribble, and it was her lucky day. Just the night before, a prospective Team MSBA member had to drop off the team, leaving a vacant spot for this energetic and charity-minded spirit. Turns out, Janelle spent her "spare time" helping to care for a delightful little girl with spina bifida named Marianne. It was kismet.

Marianne and Janelle: The Hat Trick Year

our web site www.msbaweb.org

Through three years of grueling training and relentless fundraising, Janelle raised over $30,000 for Team MSBA while completing an impressive hat trick of Boston Marathon finishes. She was one of only two three-timers on the team, and proudly held the unofficial title of social chairperson for our band of runners. But, having spent dozens of hours jogging side-by-side this strong woman, I know the fuel behind her treks from Hopkinton to Boston were thoughts of Marianne. She reasoned that the harder she worked, the more money she would raise, and the more Team MSBA could help her little friend and others like her.

The logic worked. In fact, before the 2004 Boston Marathon, Janelle and Marianne's mother, Joanne Mead, approached the MSBA Board of Directors with an interesting proposal. They asked that for every dollar over the minimum $2,500 Janelle would raise, that $.75 would directly finance the remodeling of the Mason-Rice School playground in Newton, making it accessible for Marianne and all other children with disabilities.

The MSBA determined that this accessibility (and inclusion) project was in line with our mission and agreed to the proposal. Today, Joanne's committee is finalizing plans and working toward the goal of installation in the spring. They are collaborating with the school social worker to incorporate a unit on accessibility into the K-5 curriculum and the art teacher is going to have each child in the school create a ceramic tile to be placed in a playground wall next to a quote about inclusion.

Through Janelle's hard work, the MSBA is honored to be providing over $9,000 in contributions, a major portion of the funding for this amazing project. We hope this will be the first in a future of many joint community endeavors with the MSBA.

We also hope to generate some local press around our collaboration on the effort (perhaps during a ground-breaking ceremony in the spring). More importantly, our hope is that this playground will allow Marianne and others to play in a fully accessible and inclusive environment. Janelle would say that is worth a few sore bones.

Thank you, Janelle, for the selfless sacrifices you have made to help the MSBA and Marianne.

HOME MODIFICATION LOANS FOR INDIVIDUALS WITH DISABILITIES

BY ROBIN HARTWELL

I am the mother of a 14 year-old daughter with Spina Bifida. Recently I took advantage of a state funded program that lends money, at little or no interest, to help fund modifications to your home. I discovered this program after a visit to the Disabilities Expo in Boston.

We had both our kitchen and bathroom renovated, to make them wheelchair accessible. We now have a brand new, accessible kitchen, complete with a roll under sink and stove, as well as several counters and cabinets that are now at wheelchair height. We expanded our bathroom to allow my daughter's wheelchair to enter and turn comfortably. We also added a roll under vanity sink and a shower stall with a built in seat. These modifications have given my daughter the independence she has always wanted.

The program that funded these vital home improvements is called the "Home Modification Loan Program For Individuals With Disabilities". There are very liberal income guidelines that will determine if you qualify for 0% or 3% interest. In some cases you do not have to repay the loan until you sell your home. The funding is also avalable for apartments. For further information call 617-204-3637 or visit their web site at www.state.ma.us/mrc.

I would also be happy to answer any questions myself or share information about the modifications we made. I can be reached at 781-784-0301 or via email at robonvaca@aol.com.

WHO'S OUT THERE?

(MSBA MEMBER SPOTLIGHT)

THIS MONTH'S FEATURED MEMBERS: THE NORDAHLS

BY LAUREN NORDAHL

Welcome to my world! My name is Lauren and I live with my four fabulous children on Cape Cod. My youngest daughter Karina and I were both born with spina bifida, although it has affected our lives in very different ways. When I was born, my mother was given the familiar prognosis: she won't walk, will have developmental delays, and may not live. Luckily that doctor was very wrong. After one surgery to repair my back, I was pronounced "cured" and my mom was told I would have no further troubles. I went on to have an average childhood, unaffected by spina bifida. I was able to participate in any activities I chose and excelled at school. As an adult I enjoyed good health and a great career in the optical field. I married and had three healthy children. My mother's doctors, after seeing the results of some blood tests, hypothesized that my spina bifida might have been related to my mother's inability to process folic acid correctly. We appreciated learning this information, so we could pass it on to others who might want to investigate this issue.

Three and a half years ago, then a single parent and still enjoying good health, I adopted a beautiful little girl. Karina, now five years old, was also born with spina bifida. We found out about her while she was living in an orphanage in Eastern Europe. We decided to adopt her, and after a long journey she came home to us. Karina is now a happy preschooler who enjoys playing with her friends and siblings. A late talker, she is catching up for lost time with her constant chatter. She keeps us laughing and also challenges us. She is not afraid to tell us exactly what she wants and how she wants it! Her health is stable as I write this, but we have had our share of issues. She struggles with urinary tract infections, and a kidney infection found her hospitalized around the holidays this year. Her shunt has also given her some trouble and was revised after several months of difficulties.

We are currently facing some tough decisions regarding orthopedic surgeries. Unable to walk, Karina zooms around in her mobile stander or wheelchair or uses her amazingly fast crawling technique. She enjoys swimming, bowling, movies, and coloring. Any developmental delays she had were mostly the result of orphanage treatment, and she now shows us all just how smart she really is.

Unfortunately I was involved in an accident a few months after Karina's arrival and my spinal cord (which was tethered, although I didn't know it) was damaged. The nerves were stretched and injured. Surgery was lengthy and successful in some respects, but left me unable to walk and with severe nerve pain and damage. Once postoperative swelling went down I was able to start rehabilitation and resume walking, albeit at a very different pace from what I was used to. While I am grateful for the partial recovery I still struggle to accept what function I have lost. I am unable to participate in most of the activities I used to enjoy and require help to care for my children. Having to deal with the effects of spina bifida on my health for the first time has been hard. The limitations and disabilities that I accepted in my daughter before I even met her have taken three years for me to accept in myself.

We try to ignore the medical equipment littered around the house and focus on the positive things in life. My older children not only have a sibling who is disabled, but now a mother who is as well. This challenge has been difficult for them, but I have seen them grow into wonderful, caring and understanding young people. While our family may be unusual in some ways, we share the same joys and the difficulties as many of you. One advantage I enjoy now is that I can understand what my daughter is going through from first hand experience. There is an understanding that she is not alone, and I think that helps her to not feel so different. Although we have matching A.F.O.s, instead of matching dresses, Karina and I are like most other mothers and daughters in all of the ways that matter.

MSBA YOUTH AND ADULTS GROUP (MSBAYA) FOCUS

MSBAYA Members at Holiday Party. FrRow (l-r): Brant, Michele Scaramozza, Jen Fitz-Roy. 2nd Row: Lindsay Meuse, Cori Couture, Robyn Hand, MaryHelen Fabiszewski. 3rd Row: Dominique Savinelli, Steve Niedzwicki, Brendan Sullivan, Jen Kuhar.

By the time you read this, we hope many of you MSBAYA members will have joined us at Children's Hospital for our Open Discussion Day on February 19th. Meanwhile, the MSBA Youth and Adults Group continues to grow with each passing month. In an effort to foster that growth and to reach out to members in the western part of the state, we have been trying to have events in new locations. We decided to have our fall gathering as far west as we could manage, while still making it a day trip for everyone involved. So, on a sunny Sunday afternoon - November 7th - about 10 of us met at Chili's in West Springfield for lunch. One new member from New Hampshire joined us along with his girlfriend. It was also a treat to see a long-time MSBAYA member from Deerfield that we rarely get to see. Several other folks from western Mass. were planning to attend, but weren't able to get there at the last minute. As a result, most folks in attendance turned out to be from eastern Mass. However, we are not giving up!

Lunch in West Springfield! Clockwise, starting from bottom left corner: Michele Scaramozza, Greg Boland, Tom Hickman and Sasha, Jen Kuhar, Steve Niedzwicki, Brendan Sullivan, Robyn Hand, & Lindsay Meuse.

Our next event, the Lunch & Learn Day, is slated for another location easily reachable by our western Mass. friends — the Sturbridge Host Hotel in Sturbridge. Originally scheduled for January 8th, we had to postpone this event due to bad weather and slippery roads. This was a great disappointment, as numerous people had worked very hard to get the Lunch & Learn off the ground. 30 people from all over the state had RSVP'd for this one! Here's hoping we'll see a similar turnout - maybe even MORE people for the new date! Thankfully, the hotel was able to accommodate us and the Lunch & Learn has been rescheduled for Sunday, April 10, 2005. If you are 17 or older and have spina bifida, we want to see you there!

Please join us for this full day of speakers and enlightening discussion on topics directly related to the issues we deal with on a daily basis. Topics include nutrition and overall health, adaptive sports and recreation, and opportunities for young people through Partners for Youth with Disabilities. Be sure to RSVP, to let us know if you'll be there!

(Details in the box to the right. →)

MSBA YOUTH & ADULTS GROUP COMMITTEE

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

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

Michele Scaramozza
Phone: 339-947-7227
Email: mozzasmsba@comcast.net

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

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

LUNCH & LEARN DAY SUNDAY, APRIL 10, 2005

(THIS IS A RE-SCHEDULED EVENT, POSTPONED FROM JANUARY 8TH, DUE TO SNOW.)

Where? the Sturbridge Host Hotel, Sturbridge, MA.

When? 10:30 am - 5:00 pm

What? A day of speakers and discussions on Living a Healthier Life.

Registration begins at 10:30; Speakers begin at 11:00.

Lunch will be provided, as well as an afternoon snack.

Transportation: We strongly encourage members to carpool for this event. A limited number of spots will be available in a wheelchair accessible van being loaned to us for the day. If you need a spot in the van, please let us know when you RSVP.

RSVP: by calling the MSBA's VoiceMail line at 1-888-479-1900 or by logging on to our web site: www.msbaweb.org.

For more information on this and other events, visit the MSBA web site <www.msbaweb.org> and watch your mailbox. MSBAYA event flyers are sent to all members with s.b. who are 17 or older. If you fall into this age group, but have not been receiving flyers, we may not have your birth date in our database. To add it, please contact Matt Neal at <mattneal@alum.mit.edu>.

MEDICAL RESEARCH CORNER

BY GINNY BRIGGS

FEELINGS OF SELF-WORTH IN CHILDREN WITH SPINA BIFIDA

A recent study reports that a "positive sense of self" influences success in children with spina bifida and other physical disabilities. Among 85 children with physical disabilities, six key variables were assessed that determined "self worth".

1) Onset of Disability

2) Age

3) Severity of Disability

4) Gender

5) Social Support from Friends

6) Social Support from Parents

The study took place in Ontario, Canada, where a survey was mailed to 230 people (147 had spina bifida and 83 had spinal cord injuries). A total of 85 people responded to the survey, 69 had spina bifida and 16 had spinal cord injuries. The average age was 15 years. Based on responses to the questions, each participant received a total "self worth" score.

The results showed that the highest self-worth scores were found in the younger age groups as well as among children who perceived higher levels of social support from both friends and parents. Parental support ranked the highest in the amount of influence on self-worth scores. Onset of disability, severity of disability and gender showed no differences in overall scores.

This study suggests that parental support may be the most important factor in determining the success of children with spina bifida or spinal injuries. Though the historical role of some social work practices has been to address the "overprotectiveness" of parents, it is suggested that some parental support may be appropriate in the early adult years. Social support from friends was also deemed to be an important factor in the determination of self-worth. The study suggests reducing barriers that may prevent the cultivation of friendships, such as access to transportation and physical access to other homes could be a vital link in helping children to build relationships, thereby increasing their sense of self-worth.

In general, healthy, supportive relationships appear to be key in determining the success of children with spina bifida in this study

Reference: Antie, BJ. Factors associated with self-worth in young people with physical disabilities. Health and Social Work; 2004; 29(3): 167-175.

***RESEARCH DISCLAIMER**: The contents of this article are for informational purposes only and are not intended to replace medical diagnosis and treatment. The research provided is for educational and information purposes only. The reference to these research studies does not present an endorsement or recommendation of such studies. There are many other studies, which for various nondiscriminatory reasons, are not presented in this publication. The MSBA does not diagnose medical conditions, offer medical advice or endorse specific products, services, procedures or companies. The MSBA makes no representations or warranties with respect to quality, efficacy, safety, reliability, qualifications, or desirability of the studies or researchers, and specifically disclaims any other warranties, express or implied. If you would like to know if the information in the article is appropriate for you, consult your medical doctor.*

President's Letter — Continued from page 1

Hospital myelodysplasia clinic. This has proven to be an excellent way to reach out and find new MSBA members as well as a good way to re-introduce ourselves to those who have lost touch with the MSBA. For those of you who attend clinic at Children's, be sure to look for our table and chat with our representative. At the very least, stop by to have a cookie!

In this issue, you'll find a special color insert, showing a map of New England. It was created to illustrate the distribution of our MSBA membership. Please take a look at the map to get an idea of how many MSBA members live in your area, and don't hesitate to call your Regional Representative to introduce yourself. As you know, the best support we can provide is local support, and we intend to bring as many programs, services and outreach efforts to you as possible. Huge thanks go to Board Member Matt Neal for his hard work in updating our database and building this wonderful map!

Lastly, but importantly, please see inside for details about the First Annual MSBA Golf Tournament to be held on June 2nd at the beautiful Sky Meadow Country Club in Nashua, NH. Because the MSBA has completed its 3-year rotational program with the Boston Marathon, this event will be our largest fundraiser for 2005. We need your help: volunteering for the day of the event; providing corporate sponsor contacts; and spreading the word. Let's work together to make this a huge annual event!

As you can see, there's a lot going on within the MSBA during these cold months of winter. Stay warm. Stay healthy. And best happiness to each of you.

Go Pats!

— Brian Packard —

2005 MASSACHUSETTS SPINA BIFIDA ASSOCIATION FIRST ANNUAL

GOLF TOURNAMENT

(AND LIMITED AUCTION)

DATE: THURSDAY, JUNE 2, 2005 AT 1:30 P.M. (REGISTRATION BEGINS AT 12:00 NOON)

PLACE: SKY MEADOW COUNTRY CLUB, NASHUA, NH WWW.SKYMEADOW.COM

GOLFERS:

Would you or someone you know enjoy playing a round of golf at the exclusive Sky Meadow Country Club? It costs $15,000 to join, but you can play 18 holes for just $175 and receive the following bonuses:

- Four-person scramble format
- Complimentary Lunch and Dinner and access to Beverage Cart and Auction
- Raffle Ticket with chance to win $5,000, $10,000 or a trip to the Caribbean
- Golf contests and a MAJOR hole-in-one event
- Golf Related Freebies!

SIGN UP TODAY – THE TOURNAMENT IS LIMITED TO 36 TEAMS / 144 PLAYERS

SPONSORS:

From Major Sponsors ($3,000) to Friends of the MSBA ($100) and many levels in between, we are in need of sponsors for the event. Great advertising packages provided.

AUCTION:

We will have both live and silent auctions. Sport event tickets, services, gift certificates, etc. would all be appreciated donations for the event.

Please provide us with as many people as you know that would be interested in being a golfer, a sponsor, a volunteer or who may be able to provide an auction item. Be creative!!!! If you provide the following contact information by mail, fax, email or telephone, we will make contact ourselves with the appropriate information and forms.

CONTACT NAME:____________________________________
COMPANY NAME:____________________________________
ADDRESS:____________________________________
PHONE #: __________________ FAX #:______________
EMAIL ADDRESS:____________________________________

THANK YOU!

MSBA
c/o Patenaude & Bellerose, LLC
12 Pondview Place, Tyngsboro, MA 01879
Tel: (978) 649-8724 Fax: (978) 649-8725 Ask for Hyacinth Bellerose
Email: bellerose33@charter.net Web site: www.msbaweb.org

MSBA MEMBERSHIP INFORMATION

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

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

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

- **Who is a "Qualified Member"?** A person with Spina Bifida who 1) resides in Massachusetts or a New England state that does not have its own SBAA affiliated entity, and 2) who is actively registered with the MSBA. (See Benefits information on page 12 for more details.)
- Please send us an update whenever there are any changes to your information, including your email address!
- Members can also update their information by sending an email to mattneal@alum.mit.edu.

ARE YOU 17 OR OLDER? HAVE SPINA BIFIDA?
IF YOU HAVEN'T JOINED OUR YOUTH & ADULTS GROUP,
HERE'S A GREAT WAY TO START! JOIN US FOR...

THE MSBA YOUTH &ADULT GROUP'S LUNCH & LEARN DAY!!

SUNDAY, APRIL 10, 2005

FROM 10:30 AM - 5:00 PM
AT THE STURBRIDGE HOST HOTEL,
STURBRIDGE, MA

DETAILS ON PAGE 7

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...):

____

____

____

____

____

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

** MSBA BENEFITS PROGRAMS **

QUALIFIED MEMBERS OF THE MSBA ARE NOW ELIGIBLE FOR UP TO $1,250 A YEAR THROUGH OUR BENEFITS PROGRAM AND THE 2005 SPECIAL CONFERENCE BENEFITS PROGRAM!

WHAT IS A "QUALIFIED MEMBER"?

A person with Spina Bifida who 1) resides in Massachusetts or a New England state that does not have its own SBAA affiliated entity, and 2) who is actively registered with the MSBA. Benefits are available to only one person per Membership, unless there is more than one person with spina bifida covered under that Membership.

ANNUAL BENEFITS PROGRAM

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

A Benefits application must be submitted to the MSBA by the Qualified Member or their parent or guardian via postal mail, fax or email, and will be reviewed for approval at the following month's Board of Directors meeting. Once the application has been approved, there are two ways for a Qualified Member to receive Benefits funds:

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

OR

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

2005 SPECIAL CONFERENCE PROVISIONS

This year, Qualified Members are entitled to a **Conference Benefit of $500** (in addition to the Regular Annual Benefits Program), to be used expressly **for expenses related to attending the SBAA Annual Conference** in Minneapolis, MN., June 26-29, 2005. A further **Bonus Benefit of $250** will be granted if the member agrees to perform a service for the MSBA, such as serving on a committee, writing an article for the newsletter about Conference experiences or helping to organize an MSBA event.

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

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

MSBA BENEFITS FORM

Name: ______________________

Street Address: ____

City, State, Zip: ____

Telephone: ____________________ **Email**: _________________________________

I AM APPLYING FOR:

___ **MSBA Annual Benefit of $500**

___ Receipt Attached

___ Make check payable to enclosed provider

___ **2005 Special Conference Benefit of $500**

___ (estimate) OR ___ (final)

___ Receipt Attached OR

___ Make check payable to enclosed provider

___ **2005 Bonus Conference Benefit of $250**

___ (estimate) OR ___ (final)

___ Receipt Attached OR

___ Make check payable to enclosed provider

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

____

\+ ____________

\+ ____________

= ____________ GRAND TOTAL REQUESTED

Please tear out this application form and return it to:

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

JEAN DRISCOLL SCHOLARSHIP

APPLICATION DEADLINE: MAY 15, 2005

The MSBA Board of Directors is now accepting nominations and applications for the 3rd Annual Jean Driscoll Scholarship. The MSBA offers this program as a tribute to eight-time Boston Marathon Champion and adult with spina bifida, Jean Driscoll. The scholarship will be awarded to an MSBA member with spina bifida who best demonstrates the character and determination of the scholarship's namesake. This $1,000 award may be used for educational, developmental or assistive programs or needs.

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

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

Not Just a Canned Thank You!

The MSBA would like to send out a hearfelt Thank You to Tony and Susan Leo and all their customers at the T-Stop Superette in Lynn! Through a countertop cannister, they collected $650.00 for our cause. Many thanks to Susan, Tony and all the wonderful folks who shop in their store and think of the MSBA. We are very grateful for your support!

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 MSBA completed its short-term strategy planning this past Fall. Stay tuned for more details as to how you can help. If you are interested in helping the MSBA in any way, please contact any Board Member (contact info listed on page 2 of this newsletter).
- Plans for the MSBA's first annual Golf Tournament are in full swing. The Tournament will be held on Thursday, June 2, 2005 at the Sky Meadow Country Club in Nashua, New Hampshire. See page 9 for more information!
- Some of you may have seen members of the Board staffing the new MSBA Information Desk during the Myelodysplasia clinic at Children's Hospital in Boston. This new method of reaching out to members has been very successful so far, but we need your help! If you are interested in staffing the desk during an upcoming clinic, please let us know.
- As seen in the article on page 5, Team MSBA runner Janelle Tribble earmarked some of the funds she raised through last year's Boston Marathon to be used toward the construction of an accessible playground at the Mason Rice School in Newton, MA. The project is slated to get under way in the spring, thanks to nearly $10,000 raised by Janelle. These renovations will make the Rice School playground accessible to all. We will keep you updated on the project as it progresses.
- After serving for thirteen years as the contact person for MSBA memorials and donations, Mary Ellen Shorey is stepping down from her post. We want to thank her for her many many years of hard work.
- Due to snow, the MSBAYA Lunch and Learn Day scheduled for January 8th was postponed. The event has been rescheduled for Sunday, April 10th and we hope to see all of our older teens and adults there! We want to thank all of the volunteers who have helped to coordinate this event, especially Robyn Hand and Michele Scaramozza. We could not do it without you! We also want to thank Bob Demarus and Dana Hawke at Ride-Away Vans for loaning us an accessible van for the day.
- Don't forget to make your reservations for the annual SBAA Conference being held from June 26-29, 2005 in Minneapolis, Minnesota! Sunday, June 26th will be a day dedicated specifically to issues faced by adults with spina bifida. In addition to the standard $500 benefit, Qualified Members are entitled to apply for a special benefit for attending conference of up to $750. In order to receive the full $750, applicants will be required to provide the MSBA with community services, such as assisting with the planning of an event or writing an article for the newsletter. Don't forget to send in your Benefits Application (on page 13) early. The SBAA deadline to register for the conference is May 13, 2005. Check out the article about conference on page 4 and the SBAA's web site at www.sbaa.org for more details and conference fundraising tips.
- The MSBA is in the process of developing an online Parent Support Group on Yahoo! It should be up and running by the time you receive this newsletter. See page 16 for more information on how you can join. If you have an email address that you would like to provide for our database, or you need to update other contact information, please contact Matt Neal by calling 508-460-7647-by or emailing him at: mattneal@alum.mit.edu. We do not want to lose track of you!

SUMMER CAMP SEARCH ASSISTANCE
(UPDATED FOR 2005)

BY HYACINTH BELLEROSE

The following is a list of web sites that may be helpful in your search for a summer camp, whether it be day or overnight. There will be some overlap, but these sites should cover most of the camps in New England. We have tried to include specific references to any Massachusetts camps for children with disabilities. For the more adventurous, a few web sites for camps across the nation are also included.

START WITH:

- http://www.masscamps.com/ — GREAT RESOURCE (All camps listed by Town)
- http://www.fcsn.org/camps/2004/camp2004.html — A listing by the Federation for Children with Special Needs. Includes "What to Look for in a Camp". **A GREAT RESOURCE!** To purchase a hard copy of this Directory, send a check payable to the "Federation for Children with Special Needs", in the amount of $7, which includes shipping and handling, to FCSN, 1135 Tremont Street, Suite 420, Boston, MA 02120.

MASSACHUSETTS:

- www.easterseals.com —various camps in N.E. Many MSBAYA members are alumni of these camps and speak very highly of them. Contact Easter Seals for more info 1-800-221-6827. Also check out www.eastersealsma.org and www.eastersealsnh.org .
- www.cybercamps.com; www.computercamps.com; www.internaldrive.com — Massachusetts computer camps.
- http://www.mtholyoke.edu/proj/summermath — South Hadley, MA Summer Math program.
- http://www.hillsideschool.net/summer.htm — Marlboro, MA - academics.
- www.thepaulcenter.org — Covers substantial disabilites; follows IEP.
- http://www.masspac.org/resources/camp.htm — MA SPED camp resources.
- www.camphowe.com — 4-H camp; a division of Umass (ECHO program for children with disabilities).

REGIONAL AND NATIONAL:

- http://find.acacamps.org/finding_special_needs.htm — American Camping Association.
- http://www.campsunshine.org/; www.waban.org; www.pinetreesociety.org — Camps in Maine.
- http://www.petersons.com/summerop/select/t004se.asp — National list of medical camps.
- http://www.mysummercamps.com/camps/Special_Needs_Camps/Spina_Bifida/index.html — Camps specific to Spina Bifida (none in Massachusetts).
- http://www.allensguide.com/SpecialNeeds/ — Lists unusual camps for kids with Special Needs (e.g. drama camp for kids with Nonverbal Learning Disorders) as well as international programs.
- www.campgrotonwood.com — Groton, MA and Maine.
- www.travel.com/Recreation/Camps/Special_Needs; www.adaptiveadventures.org — National listing, if you are interested in an out of state camp.

If you have had a great or terrible experience with a camp, please send us a note to put into the spring issue of the newsletter. Thanks!

Online Discussion Groups: What's available and how to sign up

By Cori Couture

Did you know that the MSBA and the SBAA offer online discussion groups for our members? Many of you have read in these pages about the MSBA Youth and Adults Yahoo!Group and how MSBAYA members use it to stay in touch and share ideas. I wanted to take a moment to tell you more about this and several other online groups you may find useful.

For those of you who are new to the world of online discussion groups, don't be intimidated. These groups (sometimes also known as mailing lists or listservs) are very simple to use and can be a fantastic resource for information and moral support when you need it most. Using email, these online groups allow people who have a common interest to converse. They are *not* chat rooms. Chat rooms require you to go to a specific online location and sign in, so that you can interact with another person or group of people in real time.

Here's how a listserv works. Someone (the list owner) decides they want to create a forum for a group of people to share ideas on a given topic - in this case - spina bifida. The owner uses a software tool to assign an online name and address to this virtual gathering of minds. The owner then assembles a list of email addresses from others who have an interest in this topic, and invites them to join the group. (If you aren't around to be invited right at the start, you can join a group that already exists. To do this, you either send a "subscribe" message to a designated email address or go to a web site and follow a set of instructions to have your address added to the mailing list for the group.)

When you want to post a message to the group, you simply write an email and send it to a single, centralized address. Then, each member of the group receives a copy of your message via email. To respond, they can just reply to the message, and again - a copy of the reply will go to every person subscribed to the mailing list.

There are many ongoing online discussions devoted to the topic of spina bifida, and we encourage you to search the web, try some different ones, and see what you find most useful. In the meantime, I offer a brief overview of four groups: ,the Spina Bifida Association of America's Youth and Adults Alliance (SBAAYAA) ListServ, the SBAA's Parents ListServ, the MSBAYA Yahoo!Group, and the BRAND NEW MSBA Parents Yahoo!Group. I'll tell you a little bit about each group or list, for whom it is intended, and how to sign up. Here's hoping you find it - and the discussions themselves helpful. I have no doubt that you will!

SBAAYAA (Youth & Adult Alliance) ListServ

What is it? The SBAAYAA listserv is a link for adults with spina bifida, young and old, to communicate with each other about a wide range of issues of common interest. Posts appear from all over the states, as well as from other parts of the world, such as Australia, Pakistan, and Guam.The best thing about this list is that people are having truly fascinating conversations all the time. If someone posts a question or problem, they don't just get a few vague replies, they get numerous thoughtful and helpful responses. The number of messages that pass through this list can be daunting, but the sheer volume of experience waiting to be tapped makes it worth the effort of skimming through them. I highly recommend this list for older teens and ALL adults with s.b.

Who's on the List 219 adults with s.b. - as of 2/14/05. This is a big list, and therefore it offers a big pool of experience!

Who Runs the List? SBAA Staff oversees this list, and they are helpful when needed. However, the members of the group are pretty self-sufficient. List members are usually able to help out other members when problems arise.

How to Sign Up! 1) Go to the SBAA's web site: www.sbaa.org.
2) On the left side of the screen, click on "eCommunities".
3) Click on the link for the Youth and Adults Alliance ListServ.
4) Follow the instructions to sign up.

SB Parents ListServ

What is it? The SB Parents Listserv is for any parent of a child who has spina bifida. Use the SB Parents list to exchange ideas, resources, debate, and have some great discussions.

Who's on the List? As of 2/14/05, 109 parents from all over the United States who have children with spina bifida are members of this list. — It's great place to get a big-picture perspective on raising a child with s.b.

Who Runs the List? SBAA Staff.

How to Sign Up! 1) Go to the SBAA's web site: www.sbaa.org.
2) On the left side of the screen, click on "eCommunities".
3) Click on the link for the SB Parents ListServ.
4) Follow the instructions to sign up.

MSBAYA Yahoo!Group

What is it? An online community for Youth and Adults in Massachusetts who have spina bifida. This group is meant to be a community where we can connect, plan activities, and generally provide support to each other. Web site address: http://groups.yahoo.com/group/MSBAYA .

Who's on the List? We currently have 60 members, ages 17 and up. This group is ONLY for folks who actually have s.b. As much as we love our parents, they are not allowed to sign up for this group. We want to make sure MSBAYA members feel they can talk about their issues without having to edit what they say.

Who Runs the List? MSBAYA Committee Member Michele Scaramozza is the Moderator for this list. Having run online groups at Partners for Youth with Disabilities, as well as for several other organizations over the years, Michele is the perfect person to oversee the MSBAYA's Online activities.

How to Sign Up! There are several ways to do this.

1) Send a blank email message to this address: MSBAYA-subscribe@yahoogroups.com .

2) Go to the Youth and Adults area of the MSBA web site http://www.msbaweb.org/msbaya.htm, click on the "Subscribe to MSBAYA" Yahoo!Groups button, and fill in your email address.

3) Send a message to Michele Scaramozza, the Group Moderator, tell her who you are and how you heard about the Group, and ask her to add your email to the mailing list. Michele's email address is: mozzasmsba@comcast.net .

MSBA Parents Yahoo!Group

What is it? A discussion group for people who are members of the Massachusetts Spina Bifida Association and who have children with spina bifida. We're here to help each other out by sharing thoughts, questions, ideas and support. Web site: http://groups.yahoo.com/group/MSBAParents/ .

Who's on the List? This group is brand new, but we've been collecting email addresses from parents for quite a while now. If everyone who has expressed an interest in the past sticks with it, we will be starting out with about 75 to 80 parents!

Who Runs the List? MSBA Vice President Hyacinth Bellerose is the Moderator for this list. This is her first time running an online discussion group, but it won't be long before parents throughout the state are talking up a storm via email.

How to Sign Up! There are several ways to do this.

1) Send a blank email message to this address: MSBAParents-subscribe@yahoogroups.com .

2) Go to the Programs area of the MSBA web site http://www.msbaweb.org/programs.htm, click on the "Subscribe to MSBAYA" Yahoo!Groups button, and fill in your email address.

3) Send a message to Hyacinth Bellerose, the Group Moderator, tell her who you are and how you heard about the Group, and ask her to add your email to the mailing list. Hyacinth's email address is: bellerose33@charter.net .

Extra Yahoo!Group Features: In addition to just receiving email messages from a Yahoo!Group, you can access numerous web-based features if you have or are willing to create a free Yahoo!Profile for yourself. These features include archives of past discussions, chat rooms, group polling, shared photos, shared web links, and a group calendar. To access them, go directly to the web site for the Group in question and sign in with your Yahoo! User ID and password.

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

- **DON'T FORGET** – **Apply for your 2005 MSBA BENEFITS** (with additional funds for attending conference)! – The new and exciting $1250 benefits application is available in this newsletter on page 13. Check it out in connection with the page 4 article on why you should go to the SBAA's Annual Conference this year. See you in Minneapolis!
- **CHILDREN'S EVENTS IN AND AROUND BOSTON** – Check out BostonCentral.com and sign up for their weekly email newsletter. It will feed you a steady stream of suggestions, both mainstream and unusual, including activities that happen on a regular basis as well as special events. If a weekend is coming up and you want to do something inexpensive (especially in the summer), check out this site for the location of summer festivals, outdoor concerts, etc. Some weeks I just delete the message, because we are too busy, but other weeks I scour the state until I find the perfect weekend or summer weekday activity. Enjoy!
- **MSBA PARENTS YAHOO!GROUP** – The MSBA Youth and Adults Group has been thriving over the past several years, and it is partially due to the online connection among its members who have access to a computer. We are establishing a similar online group for MSBA Parents. Please see the article on pages 16-17, devoted to online discussion groups, and follow the instructions to join the MSBA Parents Yahoo!Group. Through this online discussion, we hope to create a forum where parents can keep in touch with each other about ideas and events, and ask other experienced parents questions. If you need assistance with joining our Yahoo!Group, you can contact me at work at 978-649-8724.
- **WHEELING WONDERS** — Wheeling Wonders is a play group designed especially for kids with physical challenges. The group was started by Chris Haley and new MSBA member Mary Varteresian in late 2003 with the intention of gathering kids with differing abilities, their brothers, sisters, friends and families. The idea is to introduce our kids to others with similar challenges, so they won't feel as alone as they sometimes do. Our goal is to have fun. Life is short, live it up! Meetings are held the 3rd Sunday of Each Month in Westminster (Central MA) unless there is a special events! Check out the web site: www.wheelingwonders.com.
- **PLANNING A VACATION OR TRAVELING WITH THE CHILDREN?** — Check out the web site: http://travelwithkids.about.com, Sign up for their email list, which offers ideas for keeping children entertained, making sure the trip is fun for the adults in tow, and addressing the general logistics of family travel. I found some suggestions for what to do while waiting in an airport and realized they would be great activities for clinic days! If you are lucky enough to be planning a local or distant vacation, you'll find some unexpected gems. For example, how else would I have found out about the most exciting new hotel in Orlando (www.nickhotel.com)? The kids will never want to leave, while parents get their own bedroom and a chance to relax at the hotel itself without everyone begging to go to Disney!
- **INTERNET REFERENCES** – The newsletter, and my articles in particular, are heavy on internet resources. I do apologize to those that do not have access to the computer or have the required computer skills. I try to include telephone numbers where available. Meanwhile, all local libraries have computers for your use and Easter Seals and agencies such as Centers for Independent Living, have computer usage courses available. Up until two years ago, I was computer illiterate, now I do not know what I would do without my keyboard at my fingertips. Also, computers are not going away! For a future article, I will include a listing of programs to assist you in purchasing and training for computer usage. If you have any experience with programs like these, I'd appreciate your input! Thanks, Hyacinth

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
February 19, 2005	Open Discussion Day	Childrens Hospital, Boston
One Wednesday/Month	**MSBA Info Desk** at Myelo Clinic (Call MSBA or the Myelo Clinic for dates)	Children's Hospital, Boston
March 7, 2005	Board of Directors Meeting	The Centres at Burlington
April 4, 2005	Board of Directors Meeting	The Centres at Burlington
April 10, 2005	**MSBAYA Lunch & Learn** (See page 7 for details)	**Sturbridge Host Hotel** Sturbridge, MA
April 15, 2005	Boston BeerWorks Fundraiser *(tentative)*	Boston BeerWorks
May 2, 2005	Board of Directors Meeting	The Centres at Burlington
May 13, 2005	**Early Bird Registration Deadline for** SBAA Annual Conference	www.sbaa.org click on "Annual Conference"
June 2, 2005	**First Annual MSBA Golf Tournament**	**Sky Meadow Country Club** Nashua, NH
June 6, 2005	Board of Directors Meeting	The Centres at Burlington
June 26-29, 2005	**SBAA Annual Conference**	**Minneapolis, MN**

SPECIAL CONTRIBUTIONS

In Memory of ***Beatrice Gately:***

- Charles & Nancy Dunne of Waltham, MA

In Memory of ***Spiro Mitsios:***

- Mr. & Mrs. John Polychrones of Chelmsford, MA

In Memory of ***Ellen Walsh:***

- Steven Murphy of Centerville, MA

In Memory of ***Vanessa Callendar***:

- Geraldine Small of Somerville, MA

ITEMS FOR SALE, DONATION OR TRADE

Several members have recently mentioned that they have equipment, toys and gadgets related to spina bifida that they're looking to sell, trade or give away. So, here's your chance. If you have an item that you'd like to list, please describe the item, whether you want to sell, trade or give it away, and send it to the MSBA address on the back of this page.

FOR DONATION

Sturdy red hand-tricycle designed by Lucent Technologies Pioneers, a community service group that engineers items for use by individuals with special needs. Trike has high-back seat with straps and handy foot rests. Probably best for child at least 3 years old. If interested, call Brian or Cara Packard at 978-683-6644.

MASSACHUSETTS SPINA BIFIDA ASSOCIATION

733 Turnpike Street, #282
North Andover, MA 01845

Phone: 888-479-1900

Web Site: www.msbaweb.org

NEWSLETTER DEADLINE

MARCH 19, 2005

PLEASE SUBMIT ARTICLES AND INFORMATION FOR PUBLICATION TO:

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

UPDATE YOUR MEMBERSHIP TODAY!

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

(SEE PAGES 10-11 FOR DETAILS)

NEWSLETTER EDITOR: CORI COUTURE

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