



MASSACHUSETTS SPINA BIFIDA NEWS

Fall 2003

A PUBLICATION OF THE MASSACHUSETTS SPINA BIFIDA ASSOCIATION
MEMBER OF THE SPINA BIFIDA ASSOCIATION OF AMERICA

LETTER FROM THE PRESIDENT

The last few months have been both exciting and demanding for the MSBA.

After many years of dedicated service, Paul Constantino resigned as President and Board Member of the MSBA. On behalf of the Board of Directors, I would like to express our most sincere thanks for the hard work Paul put into the MSBA over almost a decade. His dedication revitalized this organization and set the stage for an impressive rebuilding process.

We also extend our heartfelt thanks to Amy Constantino, who has retired from her post as Newsletter Editor, for all her efforts over the years on this award-winning publication, and on many other projects.

We truly appreciate all that the Constantinos have done for the MSBA and look forward to building on the foundation they have laid for us.

At our October Board meeting, we held new Officer elections with the following results (all Officers were unanimously elected):

- Brian Packard - President
- Hyacinth Bellerose - Vice President
- Brendan Sullivan – Treasurer
- Jen Kuhar - Clerk

I know I speak for each of the Officers when I say that we are honored by the responsibilities of these posts and look forward to

helping the MSBA become stronger during our terms.

We are already hard at work re-vamping our committee structure and revisiting both our strategic plan and Bylaws to ensure they reflect the collective goals of the MSBA as a whole. Please do not hesitate to let us know what we can do better (or more of) to best meet your



needs. Feel free to e-mail any of the officers at their addresses, listed on the inside cover of this newsletter or drop us a note (please notice the new mailing address).

In addition to these organizational and governance changes, we have been hard at work planning our 2004 marathon effort. April 19th, 2004 will mark the third running of Team MSBA in the Boston Marathon, which has collectively raised over \$160,000 for the MSBA in the last two years.

Our MSBA Youth and Adults Group has been quite active over the past few months, and recently held its first Roundtable Discussion Day – an overwhelming success, which will be

repeated in February. Thanks to all involved for creating such an important event.

October marked SB Awareness Month, and we again reached out to local media with the terrific materials produced by the SBAA, as well as generated grass roots support through local presentations and the placement of posters.

Plans for the Holiday Party are in full swing. Our annual gathering will be on Sunday, December 7th from 1:00 – 4:00 pm. Based on the wonderful time we had last year, the party will be hosted at the North Andover Herman Youth Center. Hope to see you there.

Lastly, you will notice a slightly different look for this Newsletter. Our new Editor, Mike Higgins, is helping us to add new regular features, such as MSBAYA Update, Calendar of Events, Board Meeting Highlights, Public Awareness Corner, Member Spotlight, National Report and other columns in a streamlined format filled with helpful content. Let us know what you think about the new look. All suggestions are more than welcome. We can always use articles, stories and a helping hand for the newsletter, so please...

GET INVOLVED!!

Best wishes for a happy and healthy Fall.

- Brian Packard
MSBA President

MSBA OFFICERS

PRESIDENT

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

VICE PRESIDENT

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

TREASURER

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

CLERK

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

BOARD OF DIRECTORS

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

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

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

Dominique Savinelli 617-549-3187
Email: dominiquesavinelli@hotmail.com

MSBA REGIONAL REPRESENTATIVES

SOUTHEASTERN MASSACHUSETTS

Volunteer Needed

CENTRAL MASSACHUSETTS

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

CAPE COD & THE ISLANDS

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

WESTERN MASSACHUSETTS

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

NORTH SHORE/MERRIMAC VALLEY

Cindy Ward 978-682-9330
25 Devon Court, North Andover MA 01845

S.B.A.A. TELEPHONE

800-621-3141

M.S.B.A TELEPHONE

888-479-1900

COMMITTEE CHAIRPERSONS

ARNOLD CHIARI INFORMATION

Kevin & Maureen Walsh 781-337-2368
67 Spring Street, Weymouth MA 02188
Also try World Arnold Chiari Malformation Association at
www.geocities.com/HotSprings/2830

BENEFITS PROGRAM (Formerly "Camperships")

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

CANISTER COLLECTIONS - VOLUNTEER NEEDED

EDUCATION/SCHOLARSHIPS

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

FUNDRAISING

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

LITERATURE & LENDING LIBRARY

Danielle Everett 781-826-4485
21 Elm Street, Pembroke MA 02359

MEDICAL ISSUES

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

MEMBERSHIP

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

MEMORIAL DONATIONS

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

PARENTS HELPING PARENTS

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

PUBLIC AWARENESS/PUBLICITY

Dominique Savinelli 617-549-3187
Email: dominiquesavinelli@hotmail.com

YOUTH & ADULTS GROUP

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

WHEELCHAIR SPORTS

Dick Crisafulli, Mass Hospital School 781-828-2440

MSBAYA: WHAT'S BEEN GOING ON?

BY BRENDAN SULLIVAN

Within the past few years, the Massachusetts Spina Bifida Association has been working to increase efforts to connect with and advocate for adults with spina bifida. During that period, four adults with spina bifida have joined the Board of Directors. We are Cori Couture of Malden, Jen Kuhar of Framingham, Dominique Savinelli of Somerville, and Brendan Sullivan of Charlestown.

Over the past year the group has grown exceptionally and attendance at all of our events is extremely encouraging. Events over the past year and a half have included a trip to the Museum of Science, lunches, bowling, a cheering section at the Boston Marathon for our runners, lunch and a movie at the Jordan's Furniture IMAX theatre in Natick, and most recently, a day of roundtable discussions in Worcester.

Many of our members also participate in an email listserv hosted by Yahoo!Groups. This listserv has been a great communication tool to share information on doctors, social and school experiences, and most importantly friendly banter and conversation.

The MSBA Youth and Adults Group has a lot more planned in the coming year. We already have most events and dates planned until next April! See page 4 for more about the group.

If anyone would like to become a member of the online community or would like more information on how to regularly participate in our gatherings, please contact any of the four of us. Our personal contact information appears on the inside front cover of this newsletter and on page 4.

We hope to see many of you soon!

MSBA BOARD MEETING NOTES

BY JEN KUHAR

In an effort to keep MSBA members up to date on what the Board of Directors discusses during meetings, we present this new column highlighting the key points of some of our discussions. The Board meets on the first Monday of each month from 7 to 9:30PM.

Members are welcome and encouraged to attend. If you are interested in attending a meeting, please contact us for more information. Here are recent meeting highlights:

- In July, Dominique Savinelli was elected to join the MSBA Board of Directors. She has become the Public Awareness Committee Chair. Welcome Dominique!
- On Friday, August 15, 2003 the State Police Bagpipe Band held a golf tournament and will donate a portion of their proceeds to the MSBA. Dominique was on hand to talk about spina bifida and the MSBA. The MSBA is very grateful for the band's generosity!
- The MSBA has obtained a number of canisters for collecting donations and plans to place them at various businesses throughout Massachusetts. If you are interested in helping out with the canister drive, please contact us.
- We are working with Boston Children's Hospital in hopes of setting up an MSBA information table at their spina bifida clinic.
- Keep a look out for the new MSBA logo that is in the works!
- We have been busy updating our membership database. Many of you have received a phone survey or a mailer. We appreciate your participation. Don't forget to notify us of any address or phone number changes so that we don't

CONTINUED ON PAGE 13

TEAM MSBA READY FOR BOSTON MARATHON

BY BRIAN PACKARD

This year, the Boston Athletic Association has again provided Team MSBA with 20 charity entries to the Boston Marathon. Each of our runners will be asked to obtain pledges in support of the MSBA's activities, with a minimum pledge total of \$2,500 per runner.

Currently, we have filled more than half of the slots for our charity team. We would like to fill the remaining slots with individuals associated with the MSBA or the spina bifida community in general.

If you or someone you know would be interested in running the 2004 Boston Marathon on behalf of the MSBA, please call Brian Packard at 978-683-6644 (or e-mail him at Packard44@comcast.net) as soon as possible.

Runners who are already qualified to compete in the 2004 Boston Marathon may also join Team MSBA to support our cause, and these runners do not count towards our 20 charity entries. If you know someone running next year's race as a qualified runner, ask if they'd like to also be a part of our team and support the MSBA cause. We do not ask these qualified runners to raise the full \$2,500.

We are also looking for corporate sponsors for our team. If you know of any company or organization willing to support our efforts in exchange for PR and promotional visibility, please contact Brian immediately.

MSBA members will get a chance to meet the 2004 Team MSBA at the Holiday Party and at other events leading up to the marathon.

Stay tuned for more information on events, cheering section details and on what you can do to support our efforts. Unfortunately, the Boston Athletic Association's Charity Program is a three-year rotational program. This means that after 2004, we must sit out for at least two years. So, let's do all we can to make the most of this year's running!

MSBA YOUTH AND ADULTS GROUP NEWS & NOTES

BY JEN KUHAR

The 30th annual SBAA conference was held from Sunday, June 22 through Wednesday, June 25th at the Hyatt Regency Hotel in San Antonio, Texas. As usual, there were many new surprises. The SBAA has been working diligently to add programs focused on adults living with spina bifida. This year, Tom Baroch, an SBAA board member, developed and implemented a curriculum of Roundtable



discussions specifically catered to the population of adults with spina bifida. Topics included dating and relationships, advocacy, adult medical issues, Social Security benefits, and employment. MSBA board members Brendan Sullivan and Jen Kuhar moderated two of these discussions. Brendan lead the discussion on employment skills, while Jen facilitated the one on adult medical issues.

All of these new sessions gave folks the opportunity to discuss issues related to living as an adult with spina bifida, and allowed us to share ideas and experiences to help each other. They were a huge success and the SBAA plans to expand on this concept for future conferences.

MSBA'S YOUTH AND ADULTS GROUP HOSTS ROUNDTABLES HERE

In an effort to provide folks in Massachusetts a similar opportunity to discuss living with spina bifida, the MSBA's own Youth and Adult Group held its first roundtable discussion day on Sunday, October 19, 2003. The day was hosted by Kirk Joslin, President and CEO of Easter Seals Massachusetts, and took place at Easter Seals state-of-the-art training center in Worcester. Nearly twenty people attended. Discussion topics included careers, independent living, and dating and

relationships.

Kirk Joslin, as well as Kevin Quinn, an Easter Seals job coach, provided us with a tour of the facility and spoke about the extensive training programs and resources available through Easter Seals.

MSBA member Michele Scaramozza spoke about independent living and shared some of her experiences in achieving independence as an adult with spina bifida.

Due to the positive response from this event, we have decided to have another Roundtable day on Sunday, February 15, 2004. Stay tuned to the MSBAYA Yahoo! group (<http://health.groups.yahoo.com/group/MSBAYA/>) and the MSBA website (www.msbaweb.org) for more information.

OTHER MSBAYA EVENTS AND ACTIVITIES

Overall, the MSBA's Youth and Adults Group has been busy during the past several months. On August 17th, we took a trip to Kelly's Roast Beef and the IMAX theater located in Jordan's Furniture in Natick. Also, several of our Group members attended the MSBA summer picnic back in July.

As for the coming months, there are a couple of events planned for this winter already. On Sunday, December 7, 2003, the MSBA will hold its annual holiday party at the Herman Youth Center in North Andover, MA (see details inside this newsletter or in the flyer you received earlier this month). As mentioned above, on Sunday, February 15, 2004, we will continue our Adult Roundtable discussions – location and other details to be determined.

It is our intent to hold these discussion days at least two or three times per year and social activities during some of the off months. However, to make these events successful, *we really need your input*. If you have ideas or questions, are interested in moderating a discussion, organizing an event, or helping out in any way, please let us know! Feel free to contact Cori Couture, Brendan Sullivan, Dominique Savinelli, or Jen Kuhar directly (contact info in grey box). We would be thrilled to hear your ideas!

TO INCREASE PARTICIPATION IN FUTURE EVENTS, THE MSBAYA NEEDS YOUR HELP!

Over the past year, participation in Youth and Adults Group activities has more than doubled. We have been making an effort to hold events in different parts of the state, to accommodate as many of our members as possible. Whenever we can, we assist folks who need transportation, but our available car space is limited. In order to give as many people as possible the opportunity to attend events, in as many parts of the state as possible, we are looking for volunteers to help out with transportation. (These volunteers do not have to have spina bifida!). We particularly need help in areas outside the 128/495 belt. If you are interested, please contact Cori, Brendan, Dominique, or Jen. We appreciate any assistance you may be able to provide.

We hope you are as excited as we are about the upcoming events and hope to see you all soon!

MSBA YOUTH AND ADULTS GROUP CONTACT INFO

Cori Couture

Phone: 781-321-4920

Email: coricouture@yahoo.com

Jen Kuhar

Phone: 508-620-3963

Email: jenkuhar@msn.com

Dominique Savinelli

Phone: 617-549-3187

Email: dominiqueSavinelli@hotmail.com

Brendan Sullivan

Phone: 617-241-8561

Email: ndsully01@yahoo.com

IT'S HOLIDAY PARTY TIME!!!!

MSBA 2004 HOLIDAY PARTY

SUNDAY, DECEMBER 7TH

1:00 – 4:00 PM

HERMAN YOUTH CENTER

NORTH ANDOVER, MA



MARK YOUR CALENDARS FOR A DAY OF FUN AND CELEBRATION!

Building on the wonderful time we had last year, this year's Holiday Party will again be hosted at the Herman Youth Center in the Old Center of North Andover.

The party will include food, games and crafts for the kids, a Yankee Swap, music, a special visit from Santa Claus, and other Holiday traditions for kids and adults alike. The MSBA will provide the Yankee Swap gifts for our adult members. All others who will play, please bring a wrapped gift of no more than \$10 in value.

Last year, we had roughly 60 people attend the party, the largest crowd in years. We're expecting an even more people this year. Once again, we are inviting the runners from our 2004 Team MSBA Boston Marathon team to the event, so it will be a great chance to cheer them on as they prepare for the grueling training ahead.

So, come join us for a fun day of holiday cheer! See you on December 7!

PLEASE RSVP (WITH NUMBER ATTENDING) BY EITHER:

- Returning a note to: Cara Packard, 178 Hay Meadow Road, North Andover MA 01845
- E-mailing Cara Packard at: Packard44@comcast.net.

DIRECTIONS TO THE HERMAN YOUTH CENTER IN THE OLD DOWNTOWN CENTER OF NORTH ANDOVER, MA.

FROM 495 NORTH OR SOUTH:

- Exit at Route 114 East (Exit # 42A). Travel roughly 2 miles, and take a left at Peters Street, by the Burger King.
- Drive straight through the next intersection and continue 1 mile (the road turns into Andover Street), and bear right at the fork in the road by the town green.
- At the stop sign in the middle of the small town center, take a right. Almost immediately, turn right at the parking area at the big red barn (the Center's gymnasium). You will see a sign for the Youth Center near the front door. The address is 33 Johnson Street.



FROM 93 NORTH OR SOUTH:

- Exit at Route 125 (Exit # 41) and head East/North toward North Andover. You will travel approximately 11 miles and reach the intersection of Route 114.
- Take a left and travel ½ mile to the first major intersection (Route 125 North) by the Bertucci's.
- Take a right.
- At the next light, make a right. There will be no sign, but this is Andover Street.
- Travel 1 mile, bearing right at the fork in the road by the town green.
- At the stop sign in the middle of the small town center, take a right.
- Almost immediately, turn right at the parking area at the big red barn (the Center's gymnasium). You will see a sign for the Youth Center near the front door.
- The address of the Center is 33 Johnson Street.

NAME THE NEWSLETTER AND WIN!

TO GO ALONG WITH THE NEW FORMAT OF THE MSBA NEWSLETTER, WE ARE LOOKING FOR A NEW NAME, AND NEED YOUR HELP! SUBMIT YOUR SUGGESTIONS NO LATER THAN WEDNESDAY, DECEMBER 30, 2003, AND IF YOUR IDEA IS CHOSEN, YOU WILL RECEIVE A FREE PAIR OF MOVIE TICKETS! ALL ENTRIES SHOULD INCLUDE YOUR NAME, ADDRESS AND PHONE NUMBER, AND BE MAILED TO:

MSBA
733 TURNPIKE STREET, #282
NORTH ANDOVER, MA 01845

WE ARE LOOKING FORWARD TO YOUR IDEAS AND GOOD LUCK!!!!

IT'S CONFERENCE TIME (AGAIN)!

BY HYACINTH BELLEROSE

It's time to think about next year's convention...

You may be thinking that this has to be a misprint as the convention just happened in June. It is not. Now really is the time to think about the 2004 Spina Bifida Association of America's annual Conference in Washington, D.C. By planning now for the cost of the conference and by setting aside the vacation time, you'll be more likely to be able to attend next year. I kept putting off planning this past year and the unfortunate result was not attending.

I went to my first spina bifida conference in June of 2002 when it was in Orlando. I did not attend this summer and I really regret it. Last year, while my seven year old son Nathan (with spina bifida) and I attended convention, my husband and one year old daughter stayed home. We did not know what to expect from the experience, so we decided that it would be easier and less expensive to make the trip for two instead of four. Our first trip to conference consisted only of the three lecture days and a late flight on the fourth day. Nathan enjoyed the camaraderie of being the sole recipient of my attention as well as spending our last non-conference day at Universal Studios. The trip was too quick and we were not able to enjoy the full and relaxing experience of the hotel, the location and the many people with whom we would have liked to spend more time. Next time (I'm beginning to plan for next year!), all four of us plan to attend for a full week and turn it into a family vacation.

By far and even beyond Universal Studios, Nathan's favorite memories of the trip are of Kids Camp. After three days in Kids Camp, he was ready for three more. If it were possible, Nathan would have attended Kids Camp for a fourth day rather than going to Universal Studios! The volunteers that worked the camp were very understanding of the effects of the issues our children deal with on a daily basis and were extremely supportive and encouraging throughout the program. From petting an alligator to rock climbing to cooking, the children were kept occupied with unusual but very appropriate activities.

CONTINUED ON PAGE 7

PUBLIC AWARENESS CAMPAIGN UPDATE

BY DOMINIQUE SAVINELLI

Greetings MSBA Members!

Our 2003 Public Awareness Campaign is wrapping up. We need your help to make sure that people in every city and town in Massachusetts have a chance to learn more about spina bifida.

We have posters from the SBAA, with information about spina bifida and the importance of taking folic acid to prevent it and other neural tube defects. We will provide you with as many posters as you're willing and able to post.

Your job is easy. The next time you visit your local grocery store, hang an awareness poster on the community bulletin board (or in the store window). Don't forget to check with a manager in order to post it in the right place.

Then email me when the job is done. Let me know where you've placed the posters, so we can keep track. It's that simple! You will be helping to make people in your community more aware of spina bifida and folic acid.

How do you get started? Just email me your address and I'll send you a poster - two or three or more.

My email address is:
dominiquesavinelli@hotmail.com.

2003 SUMMER PICNIC A HUGE SUCCESS

Thank you to all who attended our summer picnic on July 12th. We were happy to see both familiar and new faces and really appreciate the effort of those who had to come from a distance. We would like to make this an annual event, so any suggestions for activities, locations or food are welcome. If no new ideas are proposed, we'll use the same location and come up with different activities. Perhaps a Yankee Swap? Board games? Make your own sundae? A magician? I'd appreciate your comments and ideas on any of our social events in order to make them as enjoyable as possible for everyone.

I'm am proud to say that our events over the past year have been averaging about 60 people per event. Great work everyone. Here we go towards building a bigger and better MSBA!!!!

Hyacinth Bellerose
bellerose33@charter.net
978-649-1295

See photos on next page.

WHO'S OUT THERE?

(MSBA MEMBER SPOTLIGHT)

THIS MONTH'S FEATURED MEMBER: NATHAN BELLEROSE

My name is Nathan Bellerose.

I am 8 and I walk with crutches.

I saw the Boston Marathon this year and met the people that ran for spina bifida. My Aunt Debbie was running in the Groton Road race and I decided to run too. Some of my family and my friend Brendan Sullivan, an adult with spina bifida decided to run with me.

My Aunt Yvonne helped me train by walking with me every day.

We were all wearing race t-shirts on the race day. It was a hot day but it was fun. We came in last but we finished!

I want to keep doing races. It's too hot in the summer but I would like to do another one this fall.

I really like sports. I play soccer and baseball and now I do road races. Maybe you could join me in one someday??????

lecture halls. When you are facing a situation for yourself or your child over the coming months, imagine what it would be like to get together with hundreds of other people that truly understand your issues. There is as much to be gained from the conversations in the hallways, restaurants and roundtables as there is in the sessions that take place in the lecture halls... and that is saying a lot! I know that I sometimes feel like no one around me can really appreciate what a typical day in our lives is like. At the conference, you will realize that you are one of many people with days and issues just like yours. Believe me, meeting others who are going through the same things really .does make a difference.

CONFERENCE

CONTINUED FROM PAGE 6

As for the programs for the young adults and adults, I cannot give enough praise. One reason that I want my husband to attend is that I cannot possibly convey to him all of the information (let alone the feelings) that I encountered. Of the three or four lectures offered in each time slot, it was a difficult decision to decide which to attend. From information on the latest in medical procedures to IEP guidelines to roundtables to practical record keeping techniques, there is information on every topic you could need and even those you did not realize you needed!

I really encourage you to attend conference (your annual benefits money can be used to offset the cost of the trip) for the information in the lectures as well as for the hints, corroboration of ideas and commiseration with others outside of the

SUMMER PICNIC PHOTOS



With the arrival of the cold days of winter, it's sometimes hard to believe that summer was ever here. So, here's photographic proof. MSBA members relax at the July 12 annual summer picnic. Planning is already underway for the 2004 summer picnic, if you have any comments or suggestions, send an e-mail to bellerose33@charter.net, or call 978-649-1295.

SBAA ADVOCATES FOR GOVERNMENT FUNDING DEVOTED TO SPINA BIFIDA

BY CORI COUTURE

One of the most exciting things for me about the 2003 national Spina Bifida Conference was seeing evidence that our nation's policy makers are learning about spina bifida, and are beginning to advocate for people affected by it. Did you know that for the first time ever, the federal government is allocating money specifically to research on spina bifida?

In the summer of 2002, a Senate hearing was held on Capitol Hill, on issues related to spina bifida and other birth defects. Thanks to this hearing, and the continued efforts of the SBAA and its fundraising arm, the Spina Bifida Foundation, \$2 million was allocated to the Centers for Disease Control to create a National Spina Bifida Program. Now, the SBAA is asking all of us to help them get legislators to allocate even more (\$5 million) for the coming fiscal year.

To this end, there was a lot of discussion at conference about the impact a post card, a letter, or better yet a visit, from a constituent can have on an elected

official. At several conference events, attendees were given large, brightly colored post cards to fill out. On the front of these cards were messages like the one you see below. On the back were spaces to fill in your name, address, phone number, and a short, personal message. The SBAA collected hundreds of these cards, and has been delivering them to Members of Congress in large batches, to great effect.

In the same vein, the SBAA has a simple, online form on their web site, which offers an easy way to join these efforts and get a message to your elected representatives. Just fill out your name and address, add your personal comments to a pre-written message, and submit the form. From there, the SBAA will take care of getting the message to your legislators for you. From the SBAA's web site: www.sbaa.org, click on the bright red link near the top of the page that says: "Advocacy Alert!"

If you are interested in diving deeper into

the advocacy process, the SBAA also has a list of tips on how to effectively communicate with legislators, both while they are in Washington, *and* when they are at home in your district. To see these, visit the "Public Policy" area of the SBAA's web site, or contact me, and I'll be happy to send you a copy of materials handed out at conference.

You may not think you can make much of a difference in the way the federal government spends its money, but you can. As someone who deals with spina bifida on a daily basis, you are an expert, and represent the voice of many others. Never underestimate the power of that experience in the eyes of your Senators and Members of Congress.

For more information, contact:

Cori Couture

Email: coricouture@yahoo.com

Phone: 781-321-4920.

HERE IS AN EXAMPLE OF ONE OF THE POST CARDS HANDED OUT AT THE CONFERENCE:

Dear Member of Congress:

As someone (who) whose family every day faces the challenges and joys of spina bifida - the nation's most common, permanently disabling birth defect - I am writing to urge your support for a \$5 million allocation in FY 2004 for the National Spina Bifida Program at the Centers for Disease Control and Prevention (CDC). As you may know, individuals with spina bifida experience a host of physical, psychological and educational challenges - including paralysis, developmental delay, numerous surgeries and living with a shunt inserted in the brain to help reduce the adverse effects of this condition.

Providing \$5 million to the CDC's National Spina Bifida Program will ensure that the agency has the resources necessary to expand and promote quality-of-life programs that support people living with spina bifida so they can live fulfilling and productive lives. In addition, increased funding will support important efforts to spread the word about the role that folic acid consumption plays in the prevention of spina bifida.

HELPFUL AGENCIES AND ORGANIZATIONS

Welcome to a new regular feature of the new MSBA Newsletter. In each issue we will bring you news and information about Agencies and Organizations around the state and around the country, which provide services and assistance that may help you or your family member who has spina bifida. To offer suggestions of agencies or organizations we should include, please contact Cori Couture at 781-321-4920 or coricouture@yahoo.com, so we can get the word out to our membership.

THE SOUTHEAST CENTER FOR INDEPENDENT LIVING (SCIL)

The Southeast Center for Independent Living (SCIL) offers numerous services to all people with disabilities living in Southeastern Massachusetts. The Four Core Services, are Advocacy, Skills Training, Peer Counseling, Information & Referrals, and many other services to empower disabled people to achieve or maintain their independence and overcome obstacles.

For students with disabilities aged 14 - 22, SCIL administers the Transitioning to Adulthood Program (TAP). Students receive assistance in planning for their future after high school; driving lessons, assistance with getting into college, or getting a job, an apartment, PCAs, adaptive equipment, and more.

SCIL is located in **The Merrill Building**
66 Troy Street, Suite #3
Fall River, Massachusetts 02720

Other Contact Info: Voice/TTY: **508-679-9210**
Email: scil@choiceonemail.com
web site: www.secil.org

EASTER SEALS SCHOOL SERVICES

Easter Seals School Services can be a partner in helping your child bridge the gap between his or her disability and educational goals.

Computer skills training is strongly recommended if adaptive equipment can help make the student more employable.

SCHOOL-TO-WORK TRANSITION

Young people with disabilities face many obstacles as they transition from school to work. Early planning is crucial. Researchers have identified lack of preparedness as a key factor influencing low employment outcomes for individuals with disabilities.

Vocational planning should begin at approximately age 14 so schools can productively utilize the high school years to prepare students for their chosen career path.

A fundamental step is a vocational evaluation that determines areas of interest and ability. Preparation for the job market may include job shadowing - visiting a variety of work sites to observe specific jobs being performed - job searching, resume writing and interviewing.

Job placement and support provides practical, ongoing help in getting and keeping a good job.

ASSISTIVE TECHNOLOGY

Easter Seals Assistive Technology Specialists come to your child's school to do training, assessments and consultations.

Assistive technology is a powerful tool for allowing students with disabilities to demonstrate what they know, and for allowing them to stay in their own community schools.

OTHER PROGRAMS

AVAILABLE

Physical, occupational and speech therapy are an additional component of Easter Seals School Services.

For more information on the Easter Seals School Services Program, contact

Rosalind Fisher

Phone: **800 244-2756 ext. 851**

Email: rozf@eastersealsma.org

Information is also available on the Easter Seals web site: www.EasterSealsMa.org.

**FOR PARENTS LOOKING TO HELP BRIDGE THE GAP
BETWEEN THEIR DISABILITY AND EDUCATIONAL
GOALS; THE EASTER SEALS SCHOOL PROGRAM
CAN BE A VALUABLE RESOURCE.**

MSBA MEMBERSHIP INFORMATION

The MSBA is a nonprofit corporation founded in 1971 by a group of concerned parents of children with spina bifida. The MSBA is 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.

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

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

- Please note that MSBA financial benefits are available only to members who (1) have spina bifida, and (2) live in Massachusetts or in a New England state that does not have its own spina bifida association.
- Please send us an update whenever there are any changes in your information.
- Members can also update their information via e-mail at mattneal@alum.mit.edu.

SCHOLARSHIP APPLICATIONS BEING ACCEPTED NOW

The MSBA Board of Directors is now taking applications for the 2nd Annual *Jean Driscoll Scholarship*.

The MSBA announced this program in 2001 as a tribute to 8-time Boston Marathon Champion and adult with spina bifida, Jean Driscoll. This scholarship will be awarded to an individual with spina bifida in Massachusetts who demonstrates the character and determination of the scholarship's namesake.

The scholarship has a value of \$1,000 and may be used for educational, developmental or assistive programs or needs.

To be considered for this scholarship, please send a 1-page letter to:

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

The application letter should outline why the individual should be considered for this award. The winner will be named in early 2004 at a date and time to be announced.

During the year of this special scholarship award, the recipient will not be eligible to participate in the \$500 benefit program which the MSBA regularly distributes.

MSBA MEMBERSHIP APPLICATION/UPDATE FORM

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

Type of Membership:

- Teen or Adult with spina bifida
- Parents of Child with spina bifida (Family Membership)
- Interested Friend or Family Member
- Medical Professional

Name of person with spina bifida: _____

Date of Birth (Important -> This information helps us provide appropriate support to members of different ages): _____

Spouse/Partner Name : _____

Member Name (if different from above) _____

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 MEMBERSHIP
MASSACHUSETTS SPINA BIFIDA ASSOCIATION
733 TURNPIKE STREET, #282
NORTH ANDOVER, MA 01845

MSBA HOLIDAY COLORING CONTEST!

KIDS! BREAK OUT THE CRAYONS, AND START COLORING! YOU COULD WIN A PRIZE AT THE 2003 HOILDAY PARTY! (SEE BACK FOR DETAILS)



COLORING CONTEST!

HEY, KIDS, COLOR THE PICTURE ON THE OTHER SIDE OF THIS PAGE, THEN SEND IT TO US, AND YOU COULD WIN A GREAT PRIZE AT OUR HOLIDAY PARTY!

NAME: _____

AGE: _____

ADDRESS: _____

MAIL YOUR ENTRY TO:

**MSBA COLORING CONTEST
MASSACHUSETTS SPINA BIFIDA ASSOCIATION
733 TURNPIKE STREET, #282
NORTH ANDOVER, MA 01845**

MSBA CALENDAR OF EVENTS

DATE	EVENT	LOCATION
December 1, 2003	Board of Directors Meeting	Newton
December 7, 2003	Holiday Party (see details on Page 5)	North Andover
January 5, 2004	Board of Directors Meeting	Newton
January 15, 2004	Deadline for Winter Newsletter Submissions	See back page
February 15, 2004	Youth and Adults Group Roundtable Discussions	TBD
February 2, 2004	Board of Directors Meeting	Newton
March 1, 2004	Board of Directors Meeting	Newton
April 19, 2004	Team MSBA — Boston Marathon	Race Route!
April 19, 2004	Boston Marathon Post Race Event	Westin Hotel, Boston
May 3, 2004	Board of Directors Meeting	Newton
June, 2004	Youth and Adults Group Activity	TBD
June 7, 2004	Board of Directors Meeting	Newton
June 20-23, 2004	Spina Bifida Association of America Conference	Washington, DC
July 17, 2004	Summer Picnic	TBD
September, 2004	Golf Tournament	TBD

MSBA BOARD NOTES

CONTINUED FROM PAGE 3

lose track of you!

- We are currently working on expanding our web site – www.msbaweb.org. Members are encouraged to check the site regularly for updates.
- The MSBA Board of Directors has been very busy developing a committee structure to better serve our members. Stay tuned for more details, as we will be looking for volunteers to work on these committees.
- We have also been exploring new events, both for social occasions and for fundraising. Ideas are always welcome.

- A golf tournament is in the works for Fall 2004. Please contact any member of the board if you are interested in getting involved in this or any other MSBA event.

- The MSBA has been investigating the possibility of a clinic for adults with spina bifida coming to the Boston area.

This past spring, Mish Madsen, daughter of Dr. Madsen at Children's Hospital did a research project on spina bifida for school. On the spina bifida community's behalf, she wrote several letters to state senators and local hospitals advocating for an adult clinic. The responses that she received were encouraging. We will keep you

posted!

- On October 13, 2003, the MSBA held its Annual Meeting with officer elections.

The election results were:

President: Brian Packard

Vice President - Hyacinth Bellerose

Treasurer - Brendan Sullivan

Clerk - Jen Kuhar

Each of these officers will serve on the MSBA Board of Directors for a two-year term.

**MASSACHUSETTS
SPINA BIFIDA ASSOCIATION**

MEMBER-SPINA BIFIDA ASSOC. OF AMERICA

**733 TURNPIKE STREET, #282
NORTH ANDOVER, MA 01845**

**DEADLINE FOR
NEXT NEWSLETTER
JANUARY 15, 2004**

**PLEASE SUBMIT ARTICLES AND INFOR-
MATION FOR PUBLICATION IN THE
NEXT EDITION OF THE NEWSLETTER**

TO:

CORI COTURE

733 TURNPIKE STREET #282

NORTH ANDOVER, MA 01845

E-MAIL: CORICOTURE@YAHOO.COM

**UPDATE YOUR MEMBERSHIP
TODAY!**

**SEE THE FORM ON PAGE 11 FOR DE-
TAILS**

**MEMBER FEE IS OPTIONAL TO INDIVIDU-
ALS OR PARENTS OF INDIVIDUALS WITH
SPINA BIFIDA**

**NEWSLETTER EDITOR: MIKE HIGGINS
NEWSLETTER COORDINATOR: CORI COUTURE**

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 of 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 MSBA nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. MSBA does not endorse any specific medical regime. 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.