

MSBA NEWS



A Publication of the
Massachusetts Spina Bifida
Association

Member, Spina Bifida Association



MSBAYA Hosts Lunch and Learn Day

by Jen Kuhar

The MSBA Youth and Adults Group gathered on Saturday, October 21, 2006 for our second annual Lunch and Learn Day at the Cary Memorial Library in Lexington. The day began at 10:00AM when nearly 30 folks were greeted by MSBAYA Committee member Robyn Hand for registration. Information packets were handed out, including the day's agenda and information about the speakers for the day. Folks socialized over coffee, juice and other snacks while waiting for the day to begin.

The first discussion, "Getting the Facts and Taking Charge, Health Issues for Adults with Spina Bifida" started at 11:00 and was led by Pixie Plummer, MD, Nedda Hobbs, MD, and Mary Jo Dunleavy, RN, BSN, all from Children's Hospital Boston. You name it, they talked about it. Interactive discussions included topics such as bladder & bowel care, shunts, Arnold Chiari Malformation, skin care, bone health, weight, cancer, and folic acid. One important thing they mentioned was that women should start bone density tests at a much

earlier age than women without disabilities, and should also have their Vitamin D levels checked. Early detection is key in the prevention of osteoporosis. They urged us all to advocate



for ourselves and educate our doctors. As you can see, it was an information-packed session and there was not enough time to get through all of the topics they had planned, even though the discussions went through lunch! In fact, one of the topics on the agenda, sex and relationships, unfortunately did have to be omitted because of time constraints. But the speakers assured us they would come back another time to see us and dedicate an entire session to this topic!

Next, Robert Park, a skills trainer from Boston Center for Independent Living (BCIL), spoke about the wonderful services offered by BCIL. Did you know that BCIL will assist you with your application for accessible housing and finding PCAs? Not only did Robert talk about the many services offered by BCIL, but he talked about the importance of advocating for oneself. He has an infectious sense of humor, as he shared many of his personal experiences and his positive outlook on life and had the room roaring in laughter. For more information about BCIL, check out their Website: bostoncil.org.

The day ended with a discussion on Personal Fitness Training and exercise by Christen Mendonca, CSCS and Shari Orlando, CSCS, both from Fitness Together Ashland. One of the first things they stressed was that the concerns/challenges individuals with disabilities face in regards to exercise, are the exactly the same as those faced by able bodied people. Fitness programs should include strength training, aerobic training, flexibility, nutrition and stress management. For folks seeking facilities with accessible equipment, they suggested checking out YMCA's, JCC's and health clubs associated with learning institutions. Their session was jam packed with lots of information, and one important message we all walked away with was that exercise is important to maintaining a healthy lifestyle and there are many resources and options out there for folks with disabilities. We all need to get moving! To learn more about Fitness Together Ashland, visit their Web site www.ftashland.com.

The day came to a close at 4:00 PM. Although it was a long day, folks walked away energized by all that they had learned. **The MSBA would like to thank all of the speakers for taking the time to speak to us and the local food establishments - Peets Coffee & Tea and Not Your Average Joe's for donating food/coffee for the day. And of course, a big thanks goes out to Cary Memorial Library for their hospitality.** Their facility is beautiful. If you have not visited them, we urge you to. This was the last scheduled MSBAYA event for the year, but we hope to see you at the Holiday Party on December 3rd. Stay tuned for more information about upcoming 2007 events.

MSBAYA

Lunch & Learn





Mark Your Calendars for the 2006 MSBA Holiday Party!

Sunday, December 3, 2006 from 12:30 PM - 5:00 PM
at the Hampton Inn, Natick



Party will include:

- Lunch!
- Fun and Games for all ages!
- Special Holiday Guests!
- Coloring contest for the kids!
- Yankee Swap for Adults*
(Bring a wrapped gift worth no more than \$10)

*Adults with S.B. do not need to bring a
Yankee Swap item

****Please RSVP by Monday, November 20, 2006****



by Email edugan@msbaweb.org
by phone: 888-479-1900
Online at: www.msbaweb.org

Include the following information in your reply:

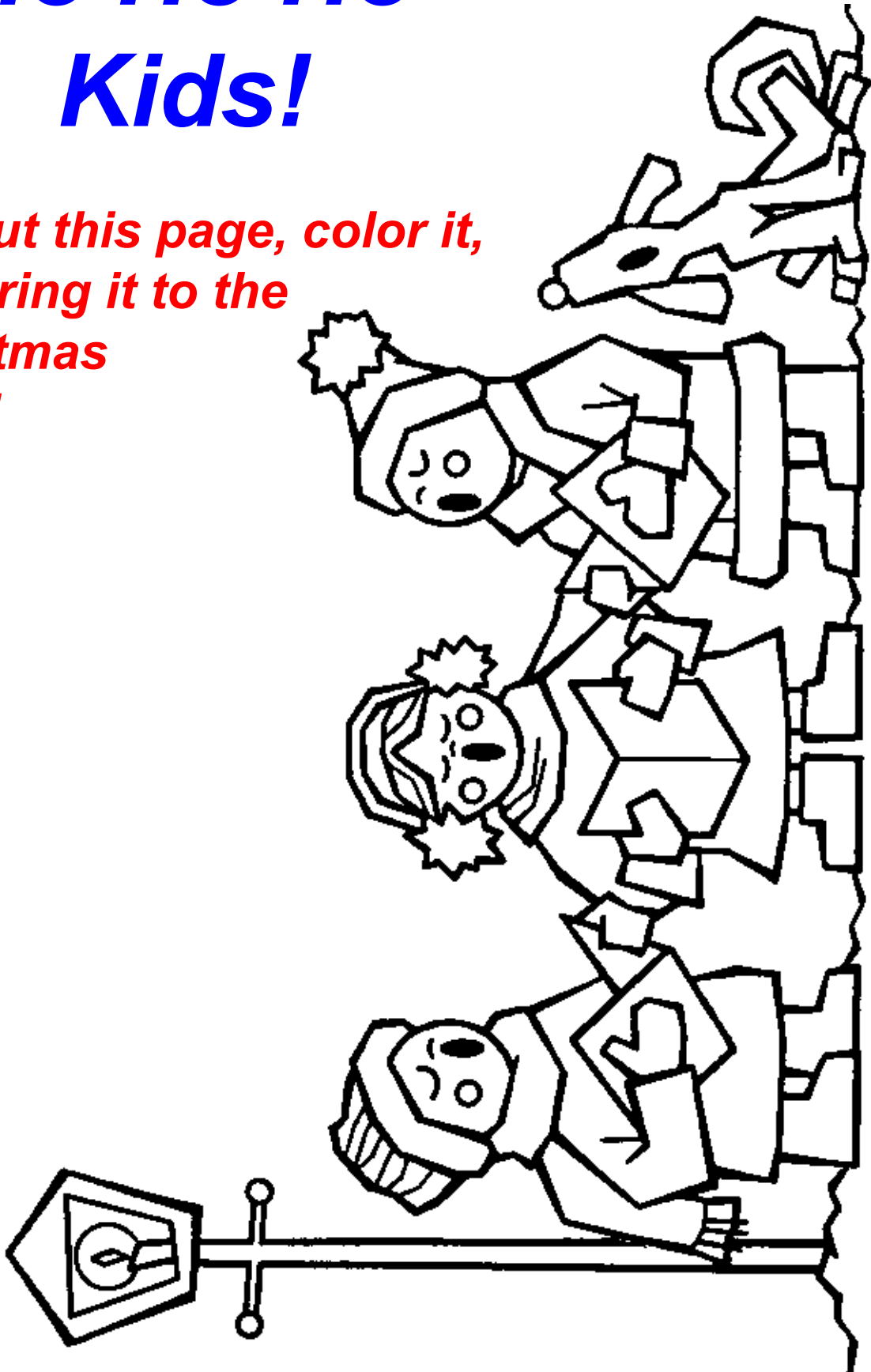
- Your first and last name
- Your phone number
- How many people are in your group
- Names and ages of everyone in your group
- Please specify the name of the person with s.b.



See Directions to the Party on the Insert!

Ho Ho Ho Kids!

***Cut out this page, color it,
and bring it to the
Christmas
party!***



Letter from the President

by Brian Packard

I am always amazed how quickly the summer comes and goes. As I write this letter, there is frost on the ground and a chill in the air. It's time to get ready for New England's 6-month winter. Meanwhile, I hope you all enjoy the colors and wonders of fall.

The MSBA held its Annual Meeting on October 2. As this is an odd-numbered year, there were no officer elections. However, the Board did review the MSBA's significant progress made toward the goals outlined in the Strategic Plan and re-visited several policies, including its conference funding program. Details on the new conference scholarship program will be announced soon.

The MSBA Youth and Adults group held its Lunch and Learn on October 21st at the Lexington library. The program hosted local healthcare and advocacy speakers, with topics ranging from fitness programs to independent living. See the front page of this newsletter for details on this excellent annual event. Thanks to the planning committee for all their hard work.

Don't forget to mark you calendars for the MSBA Holiday Party, to be held December 3rd at the Hampton Inn in Natick. As always, the day promises to be filled with fun for children and adults alike, with games, crafts and a special visit from Santa (and his helpers!) We look forward to seeing you at this ever-growing event.

Until then, I wish you health and happiness.

Brian Packard

Donate Today!

*Did you know that you
can now
donate **quickly and
securely online** using
your credit card
at
www.msbaweb.org?*

Simply go to the MSBA website
and click on the
"Make a contribution" link
on the left side of the page.

**Remember to check with
your company for corporate
sponsorship!**

Holiday Party Volunteers Needed!

THE HOLIDAY PARTY PLANS ARE IN FULL SWING
AND WE NEED YOU!!

That's right, the MSBA is already busy planning this year's Holiday Party, to be held on Sunday, December 3rd at the Hampton Inn Natick. Last year's party was a big success, thanks to the dozen volunteers who worked feverishly behind the scenes to ensure that everything went off without a hitch. **WE NEED YOUR HELP AGAIN AND THAT OF OTHERS THIS YEAR!** To get involved, please contact Jen Kuhar at jkuhar@msbaweb.org, or leave her a

message on the MSBA's voicemail.

Below is a partial list of how you can help:

- Assist with reminder phone calls
- Donate – items could include gifts for kids, craft supplies, food, items for prizes and raffles, and more.
- Shop for gifts
- Wrap gifts
- Assist with various tasks on the day of the party



THANK YOU Team MSBA !!!

by Brian Packard

On behalf of the MSBA Board of Directors and the entire spina bifida community in New England, we would like to give a heartfelt THANK YOU to the 15 members of Team MSBA who competed in the Falmouth Road Race on August 13th. Congratulations and thanks to each runner! Your training, fundraising, awareness-creation and completion of the Falmouth Road Race will help us help hundreds of families impacted by spina bifida.

A special thank you goes out to top fundraiser, Ryan Farrell, who ran on behalf of his little brother, Sean. Not only did Ryan and his family manage to raise well over \$5,000, they also showed up en masse in Falmouth to cheer on the team.

Our fundraising efforts have been amazing. It looks like we will have raised at least \$25,000 when all the donations are accounted for. And, even better news..... the Falmouth Road Race coordinators have committed to giving us another set of charity entries for the 2007 running of the race! We have asked for 5 additional entries, so our team could be as large as 20 runners next year. Most of this year's team has already asked to be a part of the team again next year, so the core of our 2007 squad is already in place. If you know of anyone interested in becoming a member of Team MSBA, the official running team of the Massachusetts Spina Bifida Association, please contact Brian Packard at bpackard@msbaweb.org.

Thank you again for all of your help and effort. I hope you had as much fun as I did.

Wheel Chair Available

Through a kind donation, an electric wheelchair with a Jay cushion and the true tack 2 system (so no one will ever tip over) in it is available. Its only 4 to 5 years old but still looks brand new! Two brand new batteries have just been put in. In addition it has an IV pole attached, however, it can be removed. If you are interested, please contact Ellen Dugan, MSBA Operations Associate (see pag 15 of this newsletter for contact information).



MSBA Holds Annual Meeting

by Jen Kuhar

Each October, the MSBA holds its Annual Meeting. During this meeting, the Strategic Plan is reviewed and the Board evaluates the Organization's progress on carrying out the Strategic Plan. Another component of the meeting includes the election of Officers. Per our by-laws, each Officer can serve 2 two-year terms in a position. The current Officers, Brian Packard, Hyacinth Bellerose, Brendan Sullivan and Jen Kuhar, are in their second year of the second term. Therefore, next year, they will not be eligible for re-election in their current position. There were no new elections at this year's meeting. Major changes in policies such as by-law revisions are also made during the Annual Meeting.

Brian Packard gave an overview of the MSBA's progress in carrying out its Strategic Plan. Areas where the MSBA will look to improve over the upcoming year are in the areas of Awareness/Education, Advocacy and Community.

Mary Jo Dunleavy, of Children's Hospital, Boston, attended the Annual Meeting. Mary Jo is on the MSBA's Medical Advisory Committee and is the Coordinator of the Myelodysplasia Clinic at Children's Hospital, Boston. The Board discussed ways in which the MSBA could further collaborate with the medical community. One project that the MSBA will look to make progress on during the upcoming year is advocating for an Adult Clinic in the Boston area.

Under the direction of the SBA, the MSBA is in the process of making changes to adhere to the new guidelines implemented by the SBA. The SBA requires all of its chapters to have the same mission statement. In order to

adhere to these guidelines, the Board voted to change the MSBA's mission statement to:

"To promote the prevention of spina bifida and to enhance the lives of all affected."

Gradually, over the next several months, the MSBA will also be looking to change its name and logo to comply with the new branding guidelines established by SBA. One of the primary purposes of the branding initiative is to allow us to become one united force, enabling us to reach more individuals affected by spina bifida. Additionally, by establishing these guidelines, it will ensure that we maintain or exceed industry standards. Look for our new name and logo coming soon!

Lastly, the Board reviewed the MSBA by-laws and Operations Manual. Changes made to the by-laws were related to our mission statement and SBA conference funding. We will be announcing our new, revamped Conference Scholarship Program in our next newsletter. The MSBA has made great progress over the past year documenting its policies and procedures in its Operations Manual and will work to complete this project during the upcoming year.

As you can see, there is a lot of work that goes on behind the scenes to run the day to day operations and to allow the MSBA to bring its many programs to its constituents. In order to grow the Organization further, we need your help. We encourage you all to get involved. Remember, all Board meetings are open to the public and we encourage you all to attend!

Upcoming MSBAYA Events

Date	Event	Location
December 3	MSBA Holiday Party -12:30 pm	Hampton Inn, Natick, MA

MSBA Youth and Adults Group Committee	
Robyn Hand Email: rlhand97@aim.com	Aimee & Brandon Shanks Email: orchid502@yahoo.com
Jen Kuhar Email: jkuhar@msbaweb.org	

ADD SOME BLING to that chair or those crutches! – Think of your chair or walker as an accessory and show your style.....

- From 11 types of cup holders to wheelchair umbrellas, check out www.edmond-wheelchair.com; they even have a close out section.
- For colors like Slime Green, Holographic Black, and Blue with Magenta Clouds. From 5 tire tread choices to a foldable wagon you can pull to the store or park. Tons more choices too! Check it out! www.colourswheelchair.com.
- For a well maintained listing of wheelchair companies, resources, troubleshooters, pre-owned equipment and other adaptable accessories, look around www.wheelchairnet.org. Even after many years in a chair, you may learn something on this site.
- If you just want lighted wheels, check ebay. I've seen 4" lighted wheels for \$45/pair or check out the following - 4 pages flashing, multicolored or just fun colors of caster at www.sportaid.com
- Don't forget the Bling being sold to spice up cell phones (Target, Claire's, etc.). It's a cheap way to add some spice to a basic metal chair. And... don't forget - if it's metal, magnets may work too!
- As for forearm crutches (Lofstrand being the original maker), I have not been able to find better products than at www.walkeasy.com. From the weight, usability and colors of the crutches to the ice pick attachments, sheepskin hand warmers and attachable bag, they cover just what you need and at reasonable prices. I have recently come upon a Canadian company www.awardprosthetics.com that has multicolor crutches (design your own) as well as a strap built into the half-arm crutch so that the

crutches aren't always dropping to the floor with a very large crash; also available are many latex free winter crutch tips. Also - GREAT customer service. This company also has folding Lofstrand crutches and many other options I have not seen before. I'll keep you updated. A luggage hitch for pulling a suitcase on wheels with crutches or "crutch skins" to change the color of your crutches at whim or three sizes of crutch bags that do not throw you off balance are available at www.fetterman-crutches.com

- Did you know that there are now crutch tips with tire/sneaker type technology to absorb the shock in the tip instead of feeling it in your elbow and shoulder???
- KNOW ANYONE FORGETFUL????? – Check out the new MEAD WRIST REMINDERS (Staples, CVS, etc.). A memo sized notebook of 21 bright blue, green and red disposable wristbands. Ours usual say "spelling book", "hand in library book", etc. We also keep a pad at school that comes home saying "catheters", "library book", etc. MAKES LIFE EASIER!!!!

REMINDER: If you do not have web access, leave a message at our toll-free 800 phone number stating (1) the item(s) under Bits and Pieces for which you would like more information; (2) your name; (3) your mailing address; (4) your phone number. The MSBA will print out the information or story and send it to you.

Please submit Bits and Pieces to Hyacinth Bellerose (contact info inside back cover).

Kids Corner

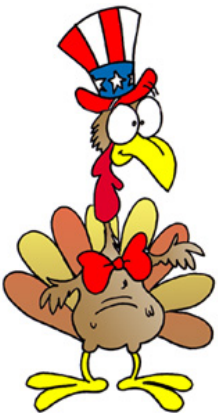


**HAPPY
THANKSGIVING!**

Watch for 2,
yes 2, special
visitors at this
year's Christmas
party!

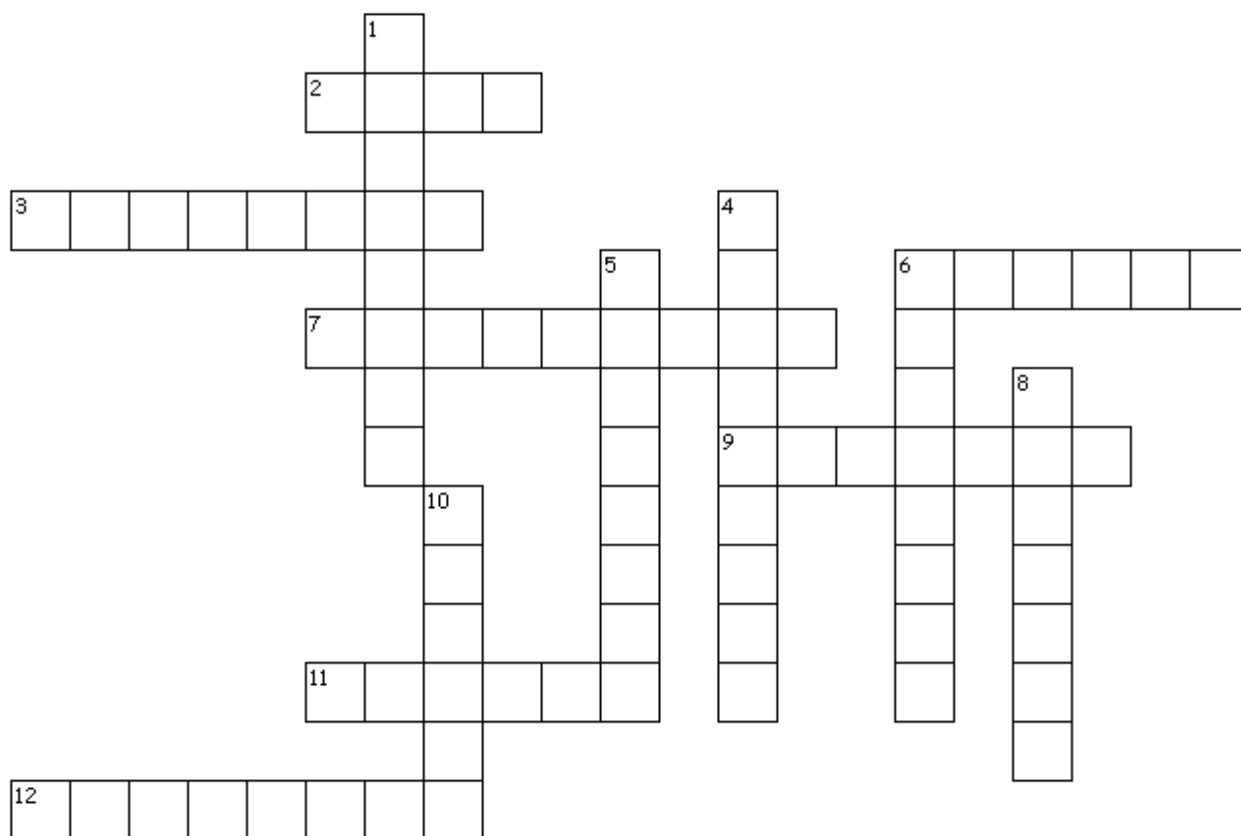


Fun Facts



- Turkeys spend the night in trees. They fly to their roosts around sunset.
- A spooked turkey can run at speeds up to 20 miles per hour. They can also burst into flight approaching speeds between 50-55 mph in a matter of seconds.
- Turkeys can drown if they look up when it is raining.
- Benjamin Franklin wanted the national bird to be a turkey.



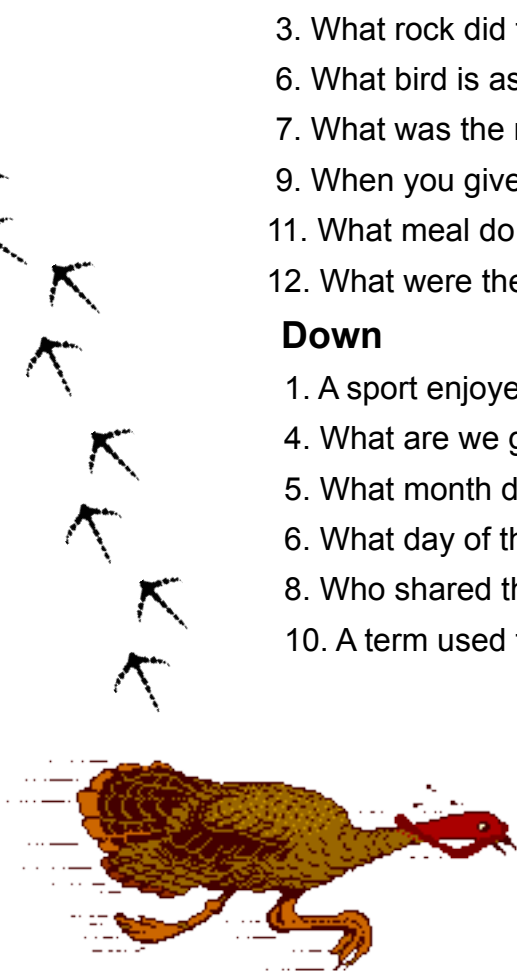


Across

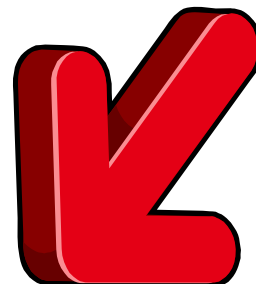
2. What vegetable made a big difference at the first Thanksgiving feast?
3. What rock did the Pilgrims land on?
6. What bird is associated with this holiday?
7. What was the name of the ship the settlers came over on?
9. When you give some of what you have to another it is called...?
11. What meal do families traditionally celebrate on this holiday?
12. What were the settlers called who came over on the Mayflower?

Down

1. A sport enjoyed on this holiday
4. What are we grateful for?
5. What month does Thanksgiving take place?
6. What day of the week does this holiday fall on?
8. Who shared the feast with the Pilgrims?
10. A term used to show appreciation



Got a joke, story
or cool fact that you'd
like to share? Ask your
parents to send it to the
editor and we'll try to put
it in the next newsletter!



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, 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.



What are the benefits of becoming a member?

- A strong Youth and Adults Group
- Fundraising
- An extensive Benefits Program
- Social Events
- A developing Parents Helping Parents program
- A Parent's Chat Group
- Online Discussion Groups
- A Lending Library

Qualified Applicants also receive:

- the award-winning MSBA quarterly newsletter
- the SBA's newsletter Insights
- may receive other MSBA benefits

Who is a "Qualified Applicant"?

- A person with Spina Bifida who resides in Massachusetts or a New England state that does not have it's own SBA-affiliated entity.
- Benefits are available to only one person per family unless there is more than one person with Spina Bifida in that family.

What does it cost?

There is NO membership fee, but tax-deductible donations are appreciated!

How do I join?

To become a member, either visit our web site and fill out the online form or fill out the application on the next page, and return it to:

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

How do I make changes to my membership?

- 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 mneal@msbaweb.org.
- 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.

***Start planning for the
SBA National Conference
June 24-27, 2007 - Louisville, KY!***



MSBA Membership Application / Update Form

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

Type of Membership:

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

Please check one:

- ☐ NEW Membership
- ☐ Renewal

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 s.b. lesion, suggestions, etc...):

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

MSBA Benefits Program

Qualified Applicants*
of the MSBA are eligible for
significant financial help each
year through our
Benefits Programs.

Annual Benefits Program

A Qualified Applicant (see Membership information on pg. 14 of this issue) 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.

How do I Apply for Benefits?

A Benefits Application must be submitted, in writing, to the MSBA Benefits Coordinator (Ellen Dugan), by the Qualified Applicant or their parent or guardian via postal mail or e-mail. The application will be reviewed for approval at the following month's Board of Directors meeting.

How do I receive Benefits funds?

Once the application has been approved, there are two ways for a Qualified Applicant to receive Benefits funds:1.

Reimbursement: The Qualified Applicant 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 Applicant 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.

Name: _____

Street Address: _____

City, State, Zip: _____

____ MSBA Annual Benefit \$500
Get \$500 Annual Benefit just by applying.*

Please tear out this
application form
and return it to:

Ellen Dugan
MSBA Benefits Coordinator
733 Turnpike Street #282
North Andover, MA 01845

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

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

Contacts

MSBA Telephone
MSBA Fax

888-479-1900
978-649-8725

SBA Telephone

800-621-3141

MSBA Officers

President

Brian Packard

Email: bpackard@msbaweb.org

Vice President

Hyacinth Bellerose

Email: hbellerose@msbaweb.org

Treasurer

Brendan Sullivan

Email: bsullivan@msbaweb.org

Clerk

Jennifer Kuhar

Email: jkuhar@msbaweb.org

Board of Directors

Matt Neal

Email: mneal@msbaweb.org

Ginny Briggs

Email: gbriggs@msbaweb.org

Peter Jablonski

Email: pjablonski@msbaweb.org

Operations

Ellen Dugan

Email: edugan@msbaweb.org

888-479-1900

MSBA Regional Representatives

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Aimee & Brandon Shanks

508-587-6788

Email: orchid502@yahoo.com

Central Massachusetts

Jean Cusick

508-756-3918

Cape Cod and the Islands

Judy Morgan

508-896-5085

Email: judjon1@comcast.net

Western Massachusetts

Betty Niedzwiecki

413-774-3489

Email: bniedzwiecki@hotmail.com

North Shore / Merrimac Valley

Cindy Ward

978-682-9330

Email: muna000@aol.com

Committee Chairpersons

Arnold Chiari Information

Kevin & Maureen Walsh

781-337-2368

Also try World Arnold Chiari Malformation Association at

<http://www.pressenter.com/~wacma/>

Benefits Program

Ellen Dugan

Email: edugan@msbaweb.org

Canister Collections

Ellen Dugan

Email: edugan@msbaweb.org

Fundraising

Hyacinth Bellerose

Email: hbellerose@msbaweb.org

Literature and Lending Library

Danielle Everett

781-826-4485

Medical Issues

Ginny Briggs

Email: gbriggs@msbaweb.org

Membership

Matt Neal

Email: mneal@msbaweb.org

Memorial Donations

733 Turnpike Street, #282

978-683-6644

North, Andover MA 01845

Parents Helping Parents

Cara Packard

Email: cpackard@msbaweb.org

Public Awareness / Publicity - VOLUNTEER NEEDED

Youth & Adults Group

Jen Kuhar

Email: jkuhar@msbaweb.org

Wheelchair Sports

Dick Crisafulli, Mass Hospital School

781-828-2440

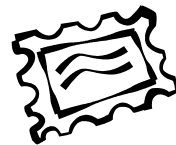
Editor: Peter Jablonski

Asst. to the Editor: Amy Blanchard

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



Massachusetts Spina Bifida Association
733 Turnpike Street, #282
North Andover, MA 01845
Toll Free Phone: (888) 479-1900
Web site: www.msbaweb.org



Calendar of Events



Date	Event	Location
December 3	MSBA Holiday Party	Hampton Inn, Natick, MA
June 24-27, 2007	SBA National Conference	Louisville, KY

The MSBA Board of Directors meets the first Monday of every month. If the first Monday falls on a major holiday, the Board meets the second Monday of the month. Meetings begin at 7:00 PM. All members are welcome.

*Mark Your Calendars for the
2006 MSBA Holiday Party!*