

Winter 2007

The Newsletter of the Spina Bifida Association of Massachusetts

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YEARS

1971-2007

Letter from the President

By Brian Packard

You have probably noticed something different in the masthead of this newsletter.....we have changed our name! That's right - we have begun the process of officially changing our name from the Massachusetts Spina Bifida Association to the **Spina Bifida Association of Massachusetts**. We are making this subtle, but important, change to comply with a branding initiative that SBA is undertaking. In order to build a unified and cohesive voice among all the chapters in the country, National has requested that each chapter adopt a standard naming convention and adopt the national Mission Statement: **"To promote the prevention of spina bifida and to enhance the lives of all affected."** Thankfully, neither of these changes are a radical departure for us, and neither of them change the core of what we do. Our chapter was created to serve the needs of every family in our region affected by sb, and we are more committed to that purpose than ever. We will continue to work closely with SBA to ensure that our growth plans are aligned with the branding and organizational goals of the entire network of chapters around the country.

Continued on page 4

And What a Party it was!

By Joyce Hillis

With the Holiday season over, I can now say that the sbaMass party was my favorite event of the season. Every year around the first of December, the seemingly never-ending holiday party season begins. This year was no different and, for me, the season began with the sbaMass Holiday Party on December 3rd. Being new to the group, I was not sure what to expect. The sbaMass Holiday party, unlike most family or work parties where you feel obligated to go, was full of people who wanted to be there. We were even lucky enough to have our Vermont friends that tried to come last year but were snowed out.

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Party continued from page 1

From the moment I came off of the elevator at the Hampton Inn in Natick, I found everyone to be so welcoming and eager to enjoy the afternoon. **Michele Scaramozza** and **Robyn Hand** professionally greeted me at the sign-in desk and, recognizing that I was new, made sure that I had a name tag so everyone would know my name and let me know what to do next. To the delight of my hungry husband, the lunch buffet was ready for us to enjoy right away. There was a variety of sandwiches, salads, chips, and plenty of yummy desserts. Luckily there were mounds of chicken fingers and french fries as many of the adults enjoyed them as much as the children!

Usually only **Santa** can make it down from the North Pole for the party, but after hearing how much fun the party was last year, **Mrs. Claus** decided to make the trip too. She and her magic dust and Rudolf ring were like magic to the children. Santa and Mrs. Claus brought so many presents that they needed almost a dozen elves to help out. Many big and bright eyes waited patiently for their turn and were very happy to let Santa know what they wanted for Christmas. Some of the answers were a surprise to the moms and dads!

After the excitement of the visit from Mr. & Mrs. Claus, **Aimee Shanks**, **Brandon Shanks**, **Lauren Nordhal**, **Denise Mearn** and **Heather Mearn** entertained the young artists by providing many craft projects. The favorite craft of the afternoon was clearly being able to design a canvas bag with paints and sparkles to take home. Boys and girls alike were thrilled to show off their artistic ability.

Taking advantage of happily busy children, the adults enjoyed a Yankee Swap. There were one or two gifts that got passed about but, from what I hear, the Yankee Swap was not as aggressive as usual! There were so many great gifts this year that almost everyone kept their own gifts. The fun filled afternoon came to an end with a raffle in which lots of great holiday gifts were given away – even a Roomba (iRobot vacuum cleaner)!

The Board of Directors would like to thank all that were involved in making this event be such a success. I know that next year when holiday party season begins, I will be looking forward to the Holiday Party 2007!!!

Donate Now!

Online donations
are safe, secure
and a
great
tax deduction!

Simply visit
www.sbaMass.org
and
click on the
Contribute link



*Thanks for your
donations to the
sbaMass
Holiday Party!*

» **Building 19 Foundation**
» **Jewel of the Nail, Holliston, MA**
» **Molly's Apothecary, Holliston, MA**
» **Necco Candy**
» **Peet's Coffee**
» **Vermont Teddy Bear Company**



*Congratulations
to all the prize
winners and kids
who participated in the
coloring contest!
We look forward to
seeing you in December!*



Letter from the President, continued from page 1

We have been lucky this winter to avoid the many cancellations we normally experience due to our famed New England weather. In fact, our Christmas party at the Hampton Inn in Natick on December 3rd had huge attendance (with people traveling from as far away as Vermont!) and was a terrific chance to get together with friends. As always, Santa and his helpers, the Yankee swap and the many arts and crafts were crowd favorites. Many thanks to the entire sbaMass Youth and Adult committee for coordinating this event.

Our next major event is the 3rd Annual sbaMass Golf Tournament to be held at the Sky Meadow Country Club on May 7. Hyacinth Bellerose and her committee are well into the planning stages for this great day, but they can always use more help. Please contact Hyci (her contact information is on the inside back cover) if you are interested in volunteering or if you know of corporate or other potential sponsors. Building on the growth of the last two years, this event is sure to be a huge awareness and fundraising success.

Keep your eyes and ears open over the next several months for some new public service announcement (PSA) advertisements now being developed by sbaMass. We have enlisted the generous support of cause

marketing specialist **Ly Weintraub** to start creating PSA's for radio, newspapers and the web. Two separate campaigns are in the works: one focusing on folic acid awareness and the other on sbaMass awareness.

Finally, I am pleased to announce that our Board of Directors has two new members: **Joyce Hillis** and **Brendan Sullivan**. Joyce's appointment to the Board is just one of many significant events she has experienced in the last few months, including marriage and passing the Massachusetts Bar. Suffice it to say that this woman has energy and will be a major asset for our Board. Brendan re-joins the Board after a brief hiatus, but he has continued to stay in close contact as our Treasurer. We are thrilled to have Brendan's wisdom and financial skills back on the team. Our Board now sits at a healthy 8-member level, fulfilling our goal for recruitment and stability.

I wish the best health and happiness to you and your family this winter season and look forward to seeing you at the golf tournament and **SBA conference on June 24th-27th in Louisville, Kentucky.**

Brian Packard

Thanks to these Special Kids!



Dear Spina Bifida Association,

A group of girls in our neighborhood decided that we would sell friendship bracelets that we made for a charity. We sold them for different amounts depending on how difficult they were to make. We thought of other charities but then we thought of spina bifida. We thought it was the best choice for us to make friendship bracelets for this charity, because a friend of ours name Katie Packard has spina bifida. We hope that you will be able to spend this \$53.40 to help people who have spina bifida.

*Sincerely,
Olivia Bertolino
Rachel Samse
Sonia Bertolino
Sophie Meyers*

Youth and Adults Group Update – We Need Your Help!

By Jen Kuhar

After an extremely busy Fall, the Youth and Adults Group Committee has taken a brief break. We are in the beginning stages of planning events for 2007 and hope to hold our first event of the Year in April. Watch your mailboxes and our website (www.sbaMass.org) for more information.

I would like to take a moment to thank Committee members **Robyn Hand**, **Aimee Shanks** and **Brandon Shanks** for their hard work during the past few years. 2006 was our most successful year yet, and we could not have done it without them!! They have generously donated their time to help the Spina Bifida Association of Massachusetts continue to bring to you numerous Youth and Adult Group programs throughout the year. **Thank you Robyn, Aimee and Brandon!!!**

The Committee is in desperate need of help. *Unfortunately, we may not be able to continue at the pace we have been going without more help.* We really do not want to cut back on our programming, but we just do not have the resources to maintain the current level of events we have been bringing to you. **PLEASE HELP US CONTINUE THE YOUTH AND ADULTS GROUP PROGRAM!** There are many ways you can help! If you are interested in helping out in any way, please contact Jen Kuhar at jkuhar@sbaMass.org. Or, you can also leave a message on the sbaMass voicemail ((888) 479-1900).

Remember to watch your mailboxes and our website for more information about upcoming events. We hope to see you soon!

Board Meeting Notes & Updates

By Jen Kuhar

Below is a summary of what the sbaMass Board has discussed over the past few months. **Board meetings are held on the first Monday of each month at 7:00PM at Panera Bread in Burlington.** All members are welcome to attend. If you are interested in attending a meeting or have any issues or concerns to be brought up at a meeting, please contact any one of us.

- The Board voted to change the Organization's name to Spina Bifida Association of Massachusetts. Our new website address is www.sbaMass.org. The Board also voted to change our logo to the same logo as SBA in order to comply with the new branding guidelines. sbaMass will continue to strive to meet the new branding guidelines set by SBA.
- Joyce Hillis has joined the Board of Directors and Brendan Sullivan, sbaMass Treasurer, has re-joined the Board of Directors.
- The Summer Picnic will be July 21, 2007. Details to be determined.
- The sbaMass Marketing campaign is in the works.
- Credentials with SBA are due in March 2007. The Board is in the process of completing this annual requirement.
- 2007 SBA Conference funding is available and completed applications are due to sbaMass no later than April 20, 2007. Seven scholarships of \$1,500 each are available. Scholarship winners will be announced at the sbaMass Golf Tournament on May 7, 2007.

Medical Research Corner

By Ginny Briggs

Do Bladder Functions Improve After Surgery For Cord Untethering?

Many of us worry about the possibility of spinal cord tethering some time in life, how to recognize it and what we can do if it happens. The general consensus in the medical community is to avoid surgery unless there are symptoms. While some people may experience changes in mobility, others may notice changes in their urinary functions. It is then that we generally discuss the possibility of surgery to release the tethered cord and perhaps restore some lost functions. Of course, surgery is not without risks and we must carefully weigh them against the benefits to decide if surgery is right for us. The bottom line is, "will this surgery be worth it?". One study published recently tried to answer this question.

A study conducted in Turkey in 2006 looked at 56 children with spina bifida who received surgery for cord untethering. Urinary functions of the patients before and after the surgery were compared. The study examined three things: dilatation (enlargement of the kidney and ureter), reflux (urine going back into the kidney) and capacity (amount the bladder holds). Six months after surgery, there were improvements seen in all three areas. Patients initially classified as having lower grade (or milder) dilatation and/or reflux improved the most after surgery. In these patients, 33% had complete resolution of dilatation and 63%

had complete resolution of reflux. Many more patients experienced significant improvement. There was also improvement and resolution seen in patients with higher grade (more serious) dilatation and reflux, but not as much. Capacity also improved by almost 40% after surgery. It was also found that the most improvement of capacity (as well as bladder pressure) was seen in children who were operated on before age 7. Overall, the surgery improved urologic functions significantly in the majority of patients.

The results of this study are encouraging, but it should be noted that other studies have found no significant improvement of urological functions after cord untethering surgery. Also, there are variations in how well patients do that are affected by things like age and severity of conditions, as shown in this study. These considerations should be discussed with our physicians to determine the best course of treatment, which may or may not include surgery.

Reference:

Does surgical release of secondary spinal cord tethering improve the prognosis of neurogenic bladder in children with myelomeningocele? Tarcun T, Onol FF, et al. Journal of Urology; Oct 2006, 176;1601-1606.

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 sbaMass nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The sbaMass 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 sbaMass does not employ medical personnel in its organization.



THANK YOU

***Susan and Anthony Leo
and the generous customers of
T-Stop Superette in
Lynn, MA!***

The Board of Director's of the Spina Bifida Association of Massachusetts would once again like to thank **Susan and Anthony Leo of Peabody** for their commitment to sbaMass. As in year's past, Susan and Anthony place a canister at the register of their superette collecting donations for sbaMass. This year the Leo's customers have donated \$600 to sbaMass to support our ongoing programs.



Spotlight on Joyce Hillis New Member sbaMass Board of Directors

Joyce McKenna Hillis was only 15 years old when her nephew Nathan was born with spina bifida. Being an integral part of Nathan's care from his multitude of surgeries as a baby to being like a big sister (as "Nana" took care of Nathan when his Mom and Dad were working) to Joyce driving a Jeep Wrangler to now teaching him how to use his ipod, Nathan has always been thrilled with his "cool aunt". Two years ago Joyce mentioned to her sister Hyacinth (mom of Nathan and Board Member) that a golf tournament would be a great idea for a fundraiser. With her connections from working at Sky Meadow Country Club, Joyce scheduled the first Golf Tournament. As a law student, she was not able to get very involved but promised to help out later. Well, it's later.....

Joyce is the newest member of the Board of Directors of the Spina Bifida Association of Massachusetts. Watching the progress of sbaMass tackling and having incredible success with the Boston Marathon while studying for final exams at the College of the Holy Cross to missing the Holiday Parties while studying for law exams at the New England School of Law, Joyce decided she had to become involved to help with keeping this incredible momentum going as soon as she could.

Graduating from law school in June, taking (and passing!) the Massachusetts bar exam in July and having her huge wedding in October (at Sky Meadow of course!), she is now working as an attorney at Patenaude & Bellerose, LLC. Joyce's new husband Michael works for his family HVAC business and enjoys finally having time with Joyce. Even with Joyce's sbaMass involvement and her considering taking the NH bar exam, Michael is very happy to report that Joyce enjoys her new found free time with him, her family and their friends. She is even learning to cook much to Mike's delight!!! Joyce and Michael take dance lessons too but don't tell Mike's grappling team!

The sbaMass has actually had an effect on Joyce's career. Joyce wanted to make a positive difference with her law degree but was not sure how. Just over four years ago, the sbaMass summer picnic was reintroduced and it was at Joyce's house. This was just after her first year of law school. Joyce then became interested in estate planning with a focus on the more difficult issues like Supplementary and Special Needs Trusts. We all look forward to when she has the experience to do a seminar for us. It might take a few years to complete the training in this difficult area but we'll be waiting!

Welcome Joyce!

Thank You

**Brown
Family Holiday Party
Raises \$5000 for
sbaMass!**

***Thanks from the Browns and sbaMass
to all those who contributed!***

Country Liquors, Holliston
Upper Falls Beverage, Newton
Isabella Groceria, Franklin
Roche Bros., Millis
Cookies to Go, Medway
Comella's of Wellesley
Gold's Gym of Millis
Dawn Carr for Arbonne International
Kelli Barker Photography, North Attleboro
Medway Gardens
Tri Valley Sports and Apparel, Medway
Brown House Books, Waltham

Jean Driscoll Scholarship

Offered by the

Spina Bifida Association of Massachusetts

The sbaMass Board of Directors is now accepting applications for the Annual Jean Driscoll Scholarship. The sbaMass offers this **\$1000.00 scholarship** as a tribute to Jean Driscoll, an eight-time Boston Marathon Champion and adult with spina bifida. The scholarship may be used for educational, developmental or assistive programs or needs and will be awarded to a sbaMass student with spina bifida who best demonstrates the character and determination of the scholarship's namesake.



Jean Driscoll, who was born with spina bifida, is an accomplished athlete and speaker who is known around the world. She has enjoyed a life many people can only dream about experiencing. Jean is an Olympic athlete who won Silver medals in the 1992 and 1996 Summer Olympic Games. She is a world record holder in the 10,000 meter track event as well as the 10K and marathon road racing distances. She has won the Boston Marathon eight times and is the only person in Boston's 105 year history to achieve this feat. She even has a street named after her in Champaign, IL and a park pavilion named after her in Urbana, IL.

PROCEDURE

1. Completed Application (including Personal Statement) and Recommendation Letter must be submitted by May 15, 2007.
2. The Personal Statement must be at least two paragraphs describing your goals in life, future educational pursuits, and anything else you feel would be helpful for the Scholarship Committee to know about you. The scholarship will be awarded to a person who, like Jean Driscoll, is achieving his/her goals despite any limitations imposed by spina bifida.
3. The recipient shall be notified of their award in mid-June and a formal announcement will be made at the sbaMass summer picnic in July.

For the OFFICIAL POSTING and APPLICATION, see www.sbaMass.org, OR email edugan@sbaMass.org, call (888) 479-1900 or fax (978) 649-8725 and request the Jean Driscoll Scholarship Package. Be sure to include your name, address, and phone number and (if available) e-mail address.



**2007 SPINA BIFIDA ASSOCIATION of Massachusetts
Third ANNUAL GOLF TOURNAMENT
SKY MEADOW COUNTRY CLUB**

Nashua, New Hampshire

DATE: May 7, 2007 at 1:30 PM

PLACE: Sky Meadow Country Club, Nashua, NH

CHARITABLE EVENT

www.skymeadow.com

GOLFERS

Our first year we had only 38 golfers; our second year we jumped to 104; this year we want a full course at 144!

- Scramble format \$175 per person; \$600 if paying for a foursome (\$100 discount)
- Lunch and Dinner provided, Beverage Carts and Snack Shack on the course
- Practice Range, Putting Contest and New Surprises!
- Bring Guests to the Dinner for \$50 per person (Auction during dinner)



➤ **WWII Airplane FLYOVER and chance to bid on a ride in one of these planes!**

SPONSORS NEEDED:

From Major Sponsors to Friends of the Spina Bifida Association of Massachusetts and many levels inbetween, we are in need of sponsors for the event.

AUCTION ITEMS NEEDED:

Sports tickets, services, gift certificates, week at vacation home, etc; be creative, be generous!

CELEBRITIES:

Do you know a sports, business or entertainment figure that would attend? If so, please contact us as soon as possible. You, this guest and the others in your foursome will be our special guests.

VOLUNTEERS:

Positions are open for assistance prior to and during the auction and dinner. Call or e-mail for meeting schedule or open positions.

SIGN UP NOW!

For details or to sign up for any of the above categories,
contact Joyce or Hyacinth (info below) or visit our
website at
www.sbaMass.org

SIGN UP NOW!

Hyacinth McKenna Bellerose, Tournament Co-Chair
Joyce McKenna Hillis, Tournament Co-Chair
Patenaude & Bellerose LLC
12 Pondview Place, Tyngsboro, MA 01879
Tel: (978) 649-8724 Fax: (978) 649-8725
Email: hbellerose@pblawoffices.com Website: www.sbaMass.org

Announcing the SBA's 34th Annual Conference!

START PLANNING NOW!

EXPANDING OUR
HORIZONS
SBA 34TH ANNUAL CONFERENCE
June 24-27, 2007 | Kentucky Convention Center | Louisville, KY

MORE DETAILS TO FOLLOW IN THE SPRING NEWSLETTER and on www.sbaMass.org and www.sbaa.org or call 1-888-479-1900 to have a package of information about Louisville and the conference mailed to you.

Flights from Boston, Providence or Manchester, NH begin at \$258 and average around \$310 on Delta, Northwest and US Airways. All flights have 1 stop.

The Galt House & Suites
140 North Fourth Street
Louisville, KY 40202
www.galthouse.com
Reservation Line: 800-843-4258
Direct Hotel Line: 502-589-5200

Single/Double/Quad Rate: \$148.36 per night (\$129.00 + plus applicable taxes)

Tell Reservationist that you are with the Spina Bifida Association Conference 2007

Registration now open at www.sbaa.org or call (800) 621-3141 for an information packet !



sbaMass Wants You to go to the SBA National Conference this June in Beautiful Louisville, Kentucky!

Funds are now available: 7 Scholarships of \$1500 each*

The SBA Conference is the biggest event of the year and *you can be a part of it!*

Apply if you want to

- meet other people living with spina bifida
- learn more about living with spina bifida
- make friends and enjoy seeing old friends
- get away to a new city
- share tips and tricks
- learn the latest medical info from doctors and other experts and

Qualifications

- Letter indicating reasons for wanting to attend the conference
- Details of persons to attend and anticipated costs
- Whether, or the number of years since, you previously attended conference (this will be a factor in determining the scholarship)
- Willingness to do article, take pictures or somehow share your experience
- Sign a contract to complete these requirements

Important Dates

SBA 2007 Annual Conference
June 24 - 27, 2007
Louisville, KY

Application Submission
Deadline: April 20, 2007

Notification Deadline to
Scholarship Awardees:
May 1, 2007

Formal Announcement at
sbaMass Golf Tournament:
May 7, 2007

See below for how to obtain the complete informational posting and an application

I WANT TO GO TO CONFERENCE!

I have reviewed the conference scholarship requirements and conference date and location. I believe I am eligible and want to submit a complete application for the conference. What next? Obtain the complete posting and application and submit complete application **NO LATER THAN APRIL 20, 2007** (*earlier submission is encouraged so that you have time to supplement your application if anything is incomplete*).

For the **OFFICIAL POSTING and/or APPLICATION (both posted on www.sbaMass.org) and/or Questions**, provide your name, address, phone number, e-mail address (if available) AND your request (SBA Conference Scholarship Package) to edugan@sbaMass.org or fax (978) 649-8725 or leave the information and request in a phone message at (888) 479-1900. Submit application to the above e-mail/fax or mail it to:

sbaMass
733 Turnpike Street, #282
North Andover, MA 01845

*See Official Posting for additional Self-Funding Options to supplement Conference Scholarship and/or to pay for conference outside of the Conference Scholarship.

Sudoku for Kids

Every row, column and mini-grid must contain the numbers 1 through 6. Don't guess - use logic!

2	1			4	3
		6	2		
		3	4		
3	4			5	6

What belongs to you, other people use it a lot,
but you hardly ever use it?
Your name!

What did the cowboy say when his dog left?
Doggone!



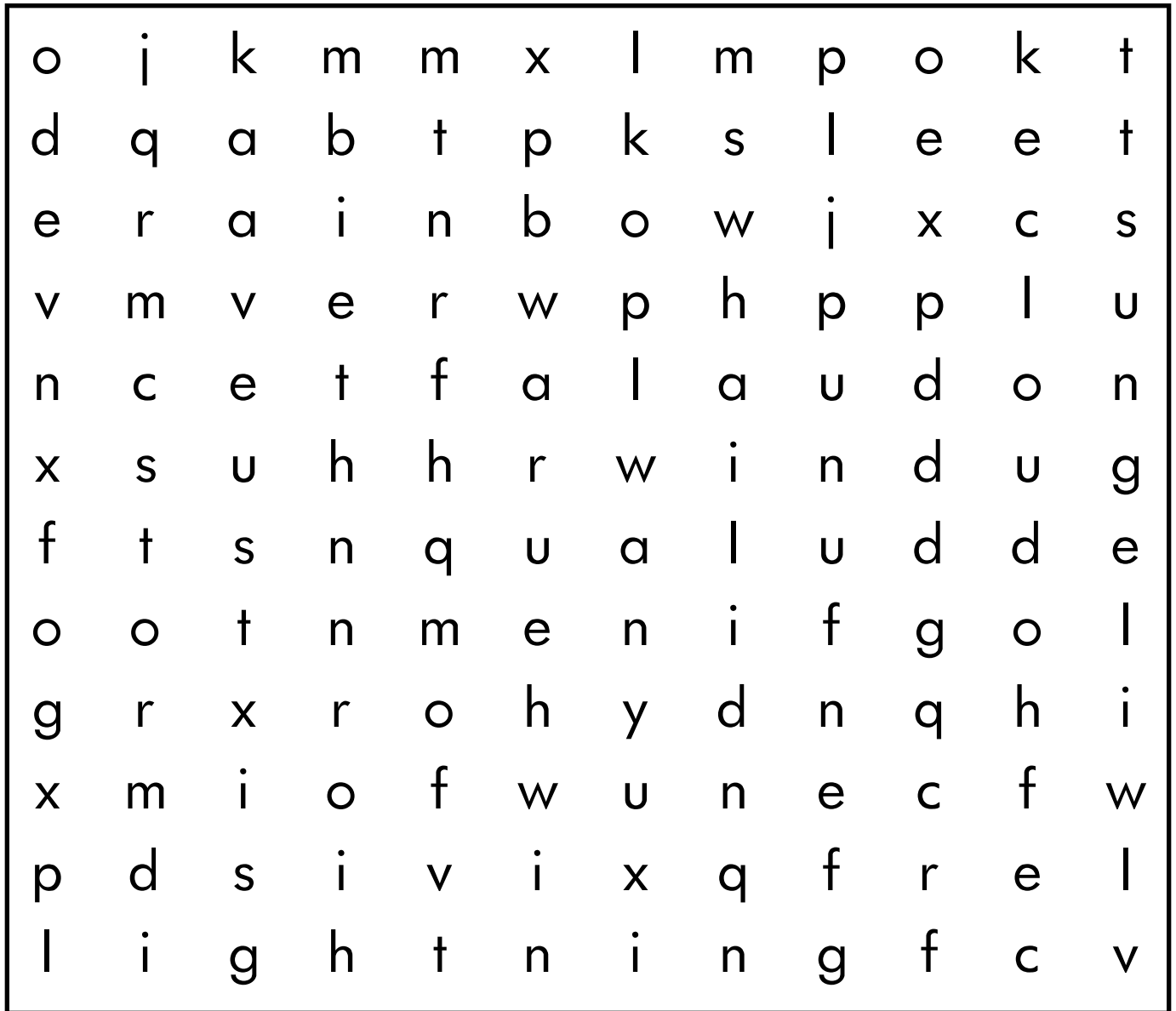
DID YOU KNOW?

Did you know that large snowflakes can measure up to 2" across and contain hundreds of individual crystals?

The largest snowflake ever found was 8" by 12"! It was reported to have fallen in Bratsk, Siberia in 1971.



The Weather



Find these words in the puzzle!

c l o u d

r a i n

s l e e t

s n o w

s u n

l i g h t n i n g

t h u n d e r

w i n d

h a i l

s t o r m

r a i n b o w

f o g

6	5	1	2	4	3
4	2	3	1	6	5
5	6	4	3	2	1
1	3	2	6	5	4
2	1	5	4	3	6
3	4	6	5	1	2

Solution

Items for Sale, Donation or Loan

Devil Dogs Have a Hand Tricycle for Loan

A hand tricycle is being donated by Devil Dogs a retired Marine Corp League, Westfield River Valley Attachment 141. The tricycle is to be loaned to a family, preferably from western Massachusetts for as long as the child can use it. When the child has outgrown the bike, it will need to be returned to the Devil Dogs, they will refurbish and loan to another child. The tricycle is designed for a child of 70 lbs or less. The Devil Dogs ask that whoever receives the tricycle, have a photo taken of the child with the tricycle for use in the Devil Dogs / Marine Corp newsletter. Please contact Ellen Dugan at (888) 479-1900 or by e-mail at edugan@sbaMass.org today!



Adult Wheelchair for Donation

An adult size gently used electric wheel chair is still available. Contact lwatson@keepingpace.com

Hand Cycle for Sale

Purchased from the catalog Abilitations, the product is the Mobility Aid Trike; we also have the upper trunk support and the foot support. The tricycle is in excellent condition and we are looking to sell the bike for \$275. We had to add a new foot plate for our daughter who has no leg movement but this is a quick adjustment to place the foot plates back in the original position.

Contact Ally Langmead at allylangmead@hotmail.com or (508) 259-9146 (cell).



Setting Your Sight For the Future: Strategies to Get What You Need and Most of What You Want!

Participate in a unique tele-program from the convenience of home!

- Would you like to connect with other individuals with Spina Bifida and share best tips?
- Can you talk about what your strengths are?
- What are the resources to help you be independent?
- What do you need to start today to create the life you want?

Join our telephone community for 1 hour a week for 9 weeks and discuss topics and learn strategies that will propel you into the future!

What you will gain by participating:

- Confidence and self-assurance
- Skills for managing healthcare
- How to identify your strengths and extend opportunities
- Information and resources
- How to make good decisions
- Leadership skills

Ideal participant:

- Teens and young adults with spina bifida
- Out-going and articulate
- Looking forward to the future
- Email access preferred but not mandatory

Contact: Sharon Sellet, Program Director
(513) 467-9292
sharon@perceptioncheck.com

Spina Bifida Association of Cincinnati with funding
provided by Ohio Settlement Funds
Cincinnati Bell & Business Technology Solutions

Winter session start date: February 5th, 2007

SBAC Regional Educational Conference, March 24th

The Spina Bifida Association of Connecticut is sponsoring a regional educational conference on Saturday, March 24th. The 1-day event will be held from 8:15 am to 4:00 pm at the University of Hartford Magnet School in Hartford, CT.

Visit SBAC.org for updates and more information. For specific information or questions, e-mail Marybeth@sbac.org or call (800) 574-6274.

SBA Scholarship Program

This SBA-sponsored program is open and accepting applications. Information can be found at www.sbaa.org under the Programs tab located on the left side of the home page.

All students living with spina bifida are encouraged to apply.

***Opportunities
for Everyone!***

sbaMass Membership Information

The Spina Bifida Association of Massachusetts 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 sbaMass is dedicated to promoting the prevention of spina bifida and to enhance the lives of all affected.



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 sbaMass quarterly newsletter
- the SBA's newsletter Insights
- may receive other sbaMass 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:

sbaMass 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@sbaMass.org.
- The sbaMass 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.sbaMass.org for ongoing events



sbaMass 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...):

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

sbaMass Annual Benefits Program

\$500 for 2007

Who Qualifies? What is a Qualified Applicant?

A Qualified Applicant (QA) is a person with spina bifida (or that person's parent/guardian) who resides in Massachusetts or a New England state that does not have a SBA affiliated entity.



How much is the benefit?

The benefit for 2007 is \$500 for the calendar year. Because benefits are available to each person with spina bifida, a family with more than one person with spina bifida would qualify for \$500 per person with spina bifida.

What Kinds of Expenses Qualify?

The benefit shall be used to enhance independence, increase mobility, or otherwise improve a person's life as s/he is affected by spina bifida. For example, the benefit may be used for braces, catheters, continence supplies, camp, assistive technology and/or other approved expenses.

When should I Apply for Benefits?

To apply for the 2007 benefit, the complete submission must be made via postal mail, fax, e-mail or online prior to 12:00 midnight on December 31, 2007. Submission as early in the year as possible is encouraged.

How do I Apply for Benefits?

The QA must do the following *or the application will not be approved*:

1. Complete an **official sbaMass Benefits application**.
2. Provide **proof of eligible expenses** for either Reimbursement or Direct Pay.
3. Submit prior to midnight on December 31, 2007 to the sbaMass contact information provided below.

Once your application *and* proof of eligible expenses have been received, the submission will be reviewed and voted on by the following month's Board of Directors meeting.

NOTE: Benefits applications will be returned, with an explanation, if received without proper documentation or if denied. QA may then resubmit a compliant submission.

For the **OFFICIAL POSTING and/or APPLICATION (both posted on www.sbaMass.org) and/or Questions**, provide your name, address, phone number, e-mail address (if available) AND your request (Annual Benefits Package) to edugan@sbaMass.org or fax (978) 649-8725 or leave the information and request in a phone message at (888) 479-1900. Submit application to the above e-mail/fax or mail it to:

sbaMass
733 Turnpike Street, #282
North Andover, MA 01845

Contacts

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sbaMass Fax

888-479-1900
978-649-8725

SBA Telephone

800-621-3141

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Also try World Arnold Chiari Malformation Association at

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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 sbaMass nor any parties who supply content to this publication make any warranty concerning the accuracy of any information found herein. The sbaMass 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 sbaMass does not employ medical personnel in its organization.

Mark Your Calendars!



- SBAC Educational Conference, March 24th
- sbaMass Conference Funding Deadline, April 20th
- 3rd Annual sbaMass Golf Tournament, May 7th
- Jean Driscoll Scholarship Application Deadline, May 15th
- SBA National Conference, June 24th - 27th
- sbaMass Summer Picnic, July 21st
- sbaMass Annual Benefits Deadline, December 31st
- Board Meetings, first Monday of each month



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

Toll Free Phone: (888) 479-1900

Web site: **www.sbaMass.org**