



Summer 2007

The Newsletter of the Spina Bifida Association of Massachusetts

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Letter from the President

By Brian Packard

This October, after seven years of Board service, one term as Vice President and two terms as President of the SBA of Massachusetts, I will “retire”. As I sit down to write my last Letter from the President, I look back with a true sense of accomplishment at what this organization has achieved over these years. The initiatives and organizational successes are many, and a quick scan of the www.sbaMass.org website gives a sense of how busy our talented Board, dedicated Operations Associate and dozens of volunteers have been.

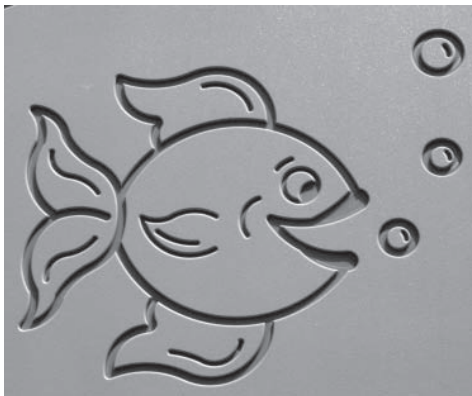
I am particularly pleased that the sbaMass has established a strong infrastructure and solid financial foundation and now operates according to a detailed strategic plan. We have built two fundraising engines (our golf tournament and running team) that ensure our expanding programs are well-funded. We have created a rich community among our youth, young adults and parents. Our award-winning website and newsletter connect our families and inform our community. But, most importantly, we have put our organization into a position where we can directly assist hundreds of families whose lives have been impacted by Spina Bifida.

I joined the sbaMass seven years ago declaring to the Board that “I have a lot of energy” and I sincerely hope that I have been able to direct that energy positively to build a better and stronger organization. I thank the Board, Ellen and all our volunteers for driving our mission with passion. And, I thank my family (especially my wife, Cara) for putting up with all the late nights and weekend hours. When I sit down at the computer to do work, my kids ask me whether I am doing my “Spina Bifida job” or “the other job”. If it is Spina Bifida work, I tell them it is the job that pays me with something other than money.

It has been a true honor and pleasure to serve the sbaMass and I know that the organization will continue to thrive in the years ahead under the talented leadership of your Board and Officers.

In other news, reports from this summer’s SBA National Conference in Louisville, Kentucky have been very positive, with our chapter’s

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Thanks to Our Sponsors for Your Continued Support!

- Polar Beverages
- Museum of Science
- IMAX Jordan Theater
 - StoryLand, NH
- Strawberry Banke, NH
 - Davis Farmland
- Roger Williams Zoo
- Children's Museum, Providence RI
- Boston Children's Museum





A PERFECT SUMMER DAY IS WHEN THE SUN IS SHINING,
THE BREEZE IS BLOWING, THE BIRDS ARE SINGING, AND THE
LAWN MOWER IS BROKEN.
- JAMES DENT



THERE'S NEVER ENOUGH
TIME TO DO ALL THE
NOTHING YOU WANT.
- CALVIN
FROM CALVIN AND HOBBS

2007 Jean Driscoll Scholarship Recipient - Amie Pantano

by Peter Jablonski

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



Jean Driscoll

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

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

Congratulations Amie!



sbaMass President Brian Packard presents certificate to Amie Pantano

Having been born with Spina Bifida, Amie Pantano always had a different outlook on life than her family and peers. She has been faced with challenges and obstacles which other people were sometimes not able to understand. It was clear that she would have to work harder to live her life and complete actions that others took for granted.

Despite the physical and mental challenges, Amie has not allowed Spina Bifida to define who she is as an individual. She has played local soccer for eight years, acts in school and town plays, participated in a water skiing team for two summers and is a member of the National Honor Society. Most recently, she has worked as an assistant teacher and personal aid at Stoney Brook Children's Center in Georgetown, MA where she has faced some of the same physical challenges she experiences everyday.

Amie plans on majoring in Elementary Special Education at Keene State College and we all wish her the best of luck in her future pursuits!

Youth and Adults Group Update

Ready for Fall!

Jen Kuhar

Wow, time flies when you're having fun, doesn't it? This summer has been another great one for the SBA of Massachusetts Youth and Adults Group. On June 9th we met at the Burlington Mall for a scavenger hunt! Folks were divided into three groups and scoured the mall for answers to various questions such as: What is the scent of the month at Yankee Candle? Or, what is the best selling pretzel flavor at the pretzel shop? Folks got bonus points if they came back with a bottle of folic acid! Since folks had such a great time and many laughs, don't be surprised to see another scavenger hunt in the near future! In July, at the annual summer picnic, many of us met up again at the beautiful (and accessible!) Danehy Park. We enjoyed delicious food and the

opportunity to sit back, relax, watch the kids, and just socialize. We could not have asked for a more beautiful day!



Have a gumball Dad!

Behind the scenes, the sbaMass YAG Planning Committee has been very busy finalizing locations and speakers for both the **educational day on Saturday, September 15, 2007** and our **3rd Annual Lunch and Learn** being held **Saturday, October 27, 2007**. These are two days you don't want to miss. Not only is this a great opportunity to come out and listen to some great presentations, but it is a chance to meet others facing the same challenges as yourself and to share and learn from one another. Please see pages 11 and 15 for all of the details. You don't want to miss out on these wonderful opportunities – ***Mark your calendars now, and don't forget to RSVP!***

As always, we are looking for volunteers to help keep YAG up and running. For more information on how you can apply to join the Planning Committee, please contact Ellen Dugan. Additionally, we are in need of space to hold our future events. If you know of available (accessible) space where we would potentially be able to hold our events, please contact Ellen Dugan. Thank You!

We hope to see you soon!



The Angels apparently found the Dark Knight!

A Mom's Review of the 2007 SBA National Conference

By Shannon Lagasse Cutter

In 2005 we learned our daughter had Spina Bifida. Sound familiar? Like many of you, we thought “What next?” From that moment on the only thing we could do was move forward with support from family and friends. We promised our daughter to do everything we could to maximize her quality of life. Cambry Faith was born in September 2005.

This year, the annual SBA conference was in Louisville KY. I attended the conference with hopes of meeting families and children with Spina Bifida. It was my first time attending. It was an unbelievable, uplifting experience. It was truly a well organized event.

I didn't expect the environment to have so much enthusiasm, laughter and smiles. I could see old friendships shining through and new ones beginning. It was clear that the adults and children focused on what they could do rather than what they could not do. That is definitely something we should all do.

The atmosphere was open and welcoming. It was set up to accommodate the varying levels of social interaction people wanted. I chose to meet with people of all ages and, of course, meet with families with children the same age as Cambry. As uncomfortable as first introductions can be, I found this experience to be easy. After all, we all had something in common. The conversations were open and free-flowing on many different topics regarding Spina Bifida. We shared stories, equipment information, website information, tips and techniques on procedures, child development, milestones and the list goes on. It was great to have conversations with people and make new friends without having to explain what condition my daughter had.

This is one of the few times since finding out my daughter had Spina Bifida that I knew I'd meet people who would truly understand the roller coaster of emotions I experience. There was an unspoken word of understanding and it could be seen in the facial expressions of other parents.

I attended the lectures that had to do with current issues in Cambry's life. I was amazed at how friendly and easily approachable the presenters were. They were confident in their topics with an upbeat attitude and many were aware of new procedures that could benefit the Spina Bifida population in the years to come. They suggested where to direct individual concerns and overall their lectures were very informational at appropriate lengths. I also got to see many exhibits featuring existing products that I was not aware of.

I was very eager to return home and share everything I had learned with my husband and family, and they were just as eager to hear it. In trying to educate myself on raising a child with special needs, I have found a statement that I remind myself of during difficult times. It is from Judy Winter's book, *Breakthrough Parenting for Children with Special Needs*. “You may have to grieve the loss of some big and small parenting dreams as you incorporate new dreams and expectations.”

I would encourage anyone who has not attended a Spina Bifida Association conference to try and do so. For me personally, it was an educational and spiritual experience. I just cannot say enough wonderful things about it. I am looking forward to attending again, this time with Cambry, her older sister, and my husband. Thank you to sbaMass for this amazing opportunity and support.

Beneficial (even fun!) But Not Boring!!!

By Hyacinth Bellerose

I planned on attending the Spina Bifida Association Annual Conference for only three days for leadership and delegate purposes. Unbeknownst to me until the last minute, my son had been thinking he was coming along to attend the full KidsCamp! I should have known. Changing plans at the last minute, Nathan and I spent five days in a hotel in Louisville, Kentucky. Even though it was our sixth year attending conference and I had to work remotely at night, I was pleasantly surprised. The conference still provided enough information to keep my mind from wandering and being anxious about work. I just returned to a full desk and I'm already looking forward to **next year in Tucson, Arizona!**

The city and the hotel provide variety each year but, since Nathan and I barely leave the hotel (other people do explore the city!), it is significant that the conference itself is new and exciting each year. The topics and exhibitors *appear* to be similar but:

1. It takes many years of attending conference to cover all areas of interest. There are **three lectures in each time slot** for three days!
2. The topics are so dynamic that the lectures need to be updated each year to take into account **recent research and developments**.
3. A person with Spina Bifida, their families and their **personal issues change each year**. One year a topic seems irrelevant but the following year it may make your top three list (for me, ACE procedure, transitioning, social skills).
4. SBA has been issuing development products and tools that are useful and relevant to us as individuals and to our chapter. A few of the **new tools** are a Health Care Guide for Adult with Spina Bifida, a Healthcare Guide for Parents of Children Living with Spina Bifida, a Guideline for Spina Bifida Healthcare, tools toward establishing an Adult Clinic, branding tools, etc...
5. I was not in a social mood this year as I had to keep on top of work but I ended up **exchanging more information with other parents and adults** than at any other conference. You never know....

I met a mom from New York with a two year old daughter with Spina Bifida. We met at lunch, talked generally for a few minutes and then, to our surprise, an hour and a half had passed! It showed me how important Parent to Parent meetings are!

Feeling confident after the conversation above, I approached a 20-something man and asked to take a picture of his braces. He was not shocked, embarrassed or offended. He was happy to talk about the development of his braces and was proud of the success after years of the revisions. A few of his details may solve my son's current bracing issue without surgery!

My week went on very socially from that first day on. I was a direct example this year of learning and teaching amongst the families as being an integral part of conference.

Watch for the next newsletter on further details on next year's conference location and how to attend for free!

Adopt-a-Ghost This Halloween!

Adopt-a-Ghost is a nationally-based fundraiser to increase awareness levels for Spina Bifida and to raise funds locally. This program involves the sale of small paper ghosts for \$1.00 in your community. **October is Spina Bifida Awareness Month** and we hope that this program will help get our message out.

Our organization is trying to be a part of this great program, but we need your help. There are many possibilities to find our little ghosts a new home. ***We are looking for stores who would be willing to pass on our little ghosts to their customers or display them for all to see. Or we would love to have a dedicated parent take this program to their work or their child's school.*** If you are interested please contact me directly at jhillis@sbamass.org or call (888) 479-1900. So, if you know any vendors, store owners, schools, or any way to get these little ghosts a new home, please let us know!!!

Thanks Brian!

The Board would like to express a heartfelt thank you to Brian Packard for his enthusiasm, ideas, energy and expertise in guiding the SBA of Massachusetts to reach higher and accomplish as much as possible for our community. Many of you may not know that Brian has also been serving at the national SBA level on the Finance Committee, has been traveling extensively for work, established, managed and ran in the sbaMass Boston Marathon and Falmouth Road Race teams, and has expanded his family size from three to four during his work for the sbaMass Board and as President. As much as we will miss Brian's leadership, we appreciate the time and effort given by Brian, Cara and the their immediate and extended family in making our sbaMass family as strong as it has become.

Take care and enjoy your family!

The sbaMass Board of Directors

Letter from the President

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energized and better organized than ever. The conference's educational sessions, organizational seminars and social events were all well-attended and well-received.

Also this summer, the sbaMass Annual Summer Picnic at Danehy Park in Cambridge was a great success, with arts, crafts and games for the kids and good company for everyone. Thanks to all of our corporate sponsors for their food, beverage and other donations.

On August 12th, our sbaMass running team ran for the second time in the 35th Falmouth Road Race on Cape Cod. Twenty-two runners suited up to raise awareness and funds for our cause, and the preliminary fundraising tally looks very impressive. Thanks to all our runners!

Finally, be on the lookout for some local market public relations and advertising that the sbaMass will be running in October as part of Spina Bifida Awareness Month. Through the assistance of National, we should have a strong local media presence during this important month.

Once again, I thank you for the privilege to be able to serve you. I wish each of you the very best health and happiness.

Brian Packard

We're Looking for Office Space!



The SBA of Massachusetts is seeking free or low-cost office space within the Route 495 Metrowest area. The ideal space would include 2 offices, meeting space to accommodate 20, wheelchair accessible, 24/7 access and accessible restrooms.

*Please contact Ellen Dugan, Operations Associate,
if you or someone you know can help!
(888) 479-1900 or edugan@sbamass.org*

Board Meeting Notes & Updates

By Ellen Dugan

Below is a summary of what the SBA of Massachusetts Board has discussed over the past few months. Board meetings are held on the first Monday of every other 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.

- Folic acid outreach efforts continue. On Friday June 20th the sbaMass had a Community Homestand Booth at the Red Sox game. This space is provided to non-profits from the Boston Red Sox to enhance an organizations outreach efforts. sbaMass volunteers will be back for the September 28th Red Sox game. Come by and say "Hi" if you are at the game.
- The sbaMass Annual Meeting will be held on Monday October 1st at 7:00 PM at Panera Bread in Burlington. All members are welcome to attend. The Annual Meeting includes election of officers and development of plans for the upcoming year. Hope to see you there!
- Four sbaMass constituents received scholarships to attend the Annual SBA Annual Conference in Louisville KY. Several other sbaMass constituents attended as well. As in past years much information is presented in the individual workshops as well as plenary sessions.
- Continue to log onto the sbaMass and SBA websites for changes in the website, outreach efforts and new programming.

Falmouth Road Race

A Rousing Success!

by Brian Packard

The SBA of Massachusetts Running Team suited up again on a sunny and hot Sunday August 12th to compete in the 35th running of the Falmouth Road Race on Cape Cod. Our 22-member team varied in age (teens to, well, let's just say middle-aged) and abilities (7-minute miles to more "leisurely" paces). But, every member of the team raised major awareness for Spina Bifida in our region through their fundraising campaigns. As of today, it looks like the team will clear at least \$30,000 in donations. One runner, Ryan Farrell, raised an amazing \$7,125 in honor of his little brother Sean, who has Spina Bifida. Many of the teammates gathered at a post-race party hosted by the Potts family in Falmouth (thanks Judy and Joe). After complaining about the heat and the hills, nearly all of the teammates committed to putting themselves through the same pain next year for our cause. Thank you runners!



Team sbaMass- 2007

(back L to R) Matt Lombardi; Jane Hauser; Dave Balardini; Brendan Sullivan; Michael Sullivan; Tammy Cupples; Don Martin; Mary Honan; Kathleen Brannigan; Anne Hitchcock; Jeff Hitchcock. Kneeling: Bob Bertolino; Renee Fay & children; Leanne Martin; Katie Packard; Brian Packard; Jon Paul Potts; and Christian Potts in front

Sullivan Brothers Fundraiser at Boston Beer Works - A Recap

by Brendan Sullivan

On Friday, August 3rd pool sticks were sharpened, auction items bid upon, and blueberry beer was poured once again in support of the SBA of Massachusetts. For the fifth consecutive year, Michael and Brendan hosted over 40 guests at Beerworks to celebrate their running a road race in support of the sbaMass.

While a few lucky people walked away with auction items, the sbaMass was the real winner on the evening as over \$1,500 was raised for the organization. Michael and Brendan would like to thank all of their family, friends, and guests that came to support this event once again.

Many adult members of the organization also took this evening as a social occasion to catch up with many within the organization. More than ten members of the YAG were in attendance, so if you are a member of this group please consider coming next year.

Another year, another great event, and another rewarding road race....though Falmouth was a touch easier than the Boston Marathon for us. Most important, the support of the sbaMass that is so necessary for it to fulfill it's mission was strengthened by many very kind friends.

Until next year!

YAG Presents Let's Talk!

Saturday, September 15, 2007

Topics Include:
Adaptive Winter Sports
Chronic Illness

Guest Speakers:

Daveen Balliro, RN
Tim Race

Cary Memorial Library, Lexington, MA 1-4PM

-
- RSVP by September 10, 2007 to Ellen Dugan
 - Individuals 17 and older with Spina Bifida along with their professional caregiver are invited to attend



Corinth Man Scales Peaks for Charity Climb

by Rebecca Rumph



CORINTH—What's a man to do in order to give back to the association that has been a great help to his six-year-old daughter? The solution for **John Page of Corinth** is to climb 67 of the highest peaks in Vermont, New Hampshire and Maine. In the spring of next year, he will begin to scale the peaks in order to raise awareness of and funds for Spina Bifida, a disease that afflicts his daughter Erin.

Spina Bifida is a neural tube disease, which causes the spinal cord to not fully develop in the first month of pregnancy. Erin has already had approximately 26 surgeries in her short six years.

Most women do not realize they are pregnant until after the first month when this disease takes hold. According to the Spina Bifida Association of America (SBAA), 70% of these births could be avoided if women of a childbearing age included more folic acid in their diet.

The association also says that the average cost of having a child with Spina Bifida is between \$500,000 and \$1 million. And many other problems can manifest themselves in children with Spina Bifida. Seven out of every 10,000 babies will be born with Spina Bifida and there are more than 70,000 cases in the U.S. alone.

Page was driving home from one of the many trips to the hospital he takes with Erin when he thought of hiking as a way to raise funds for the SBAA.

"My mission is to climb the highest 67 summits in New England over 4,000 feet", Page says. "It is an 18-month expedition which I expect to open a lot of eyes about Spina Bifida. I also feel that it will be a spiritual journey and a cleansing journey. I hope to touch a lot of hearts."

He hopes to raise funds for the Spina Bifida Association of Massachusetts, which is the local chapter in New England. Their website can be found at www.sbaMass.org.

Page's expedition will not be a solo adventure. He will be joined by guest climbers at times and anyone is welcome to go with him on any of the hikes. The climbs will not be technical, although for the winter climbs he anticipates using crampons and an ice ax.

And although Page has already received support from several sponsors, including Jason Stadler of Asolo, USA Inc. in Lebanon, Lowe Alpine, Black Diamond and Raven Ridge Designs, Milne Travel, he is currently looking for donations to secure the rest of the equipment he needs for the expedition. A website for the trip has been set up at www.myspace.com/climbingforspinabifida, which explains more about Page's goals for the climbing expedition.

He welcomes donations and/or gift certificates to Farm-Way in Bradford where he plans on purchasing the rest of his equipment. **Donations and/or gift certificates can be sent to John Page, 1202 Pike Hill Road, Corinth, VT 05039, or email Page at odessa@tops-tele.com.**

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CALL FOR HELP! WE NEED YOUR SKILLS!

Yes, you and your friend....
Please reach out to us by September 14th!



Want to make a difference in your life and the lives of others? Want to broaden your professional experience with volunteer work? Why not join forces with the SBA of Massachusetts!

The sbaMass Board of Directors needs your help in many areas! We are currently dedicated to establishing an integrated clinic for adults with Spina Bifida in Massachusetts. Only with your assistance can we free up time to work on the adult clinic without losing ground on our current fundraising and programming.

Our organization needs volunteers in all areas, but specifically as follows:

- **Advisory Board Members:** We are looking for a commitment to attend quarterly meetings and bring to the Board an executive skill (marketing, financial, medical, etc.).
- **Board Members:** Needed: A commitment to attend quarterly meetings and to Chair or Co-Chair a Committee.
- **Fundraisers:** People needed to locate national or local individuals as well as corporate sponsors for our events and programs. In addition, we need enthusiastic people to organize and execute these events.
- **Learning and Social Event Assistance:** Are you outgoing, energetic, and ready to have a lot of fun? Then this position is for you! Work with our staff in setting up and carrying out events for families and young adults. Help is also needed either prior to or on the day of the scheduled events.
- **Data Updates:** Calling all computer pros! Computer literate and/or telephone people needed to update our donor, friends, affiliates and member database. Privacy policy must be signed and followed.
- **Public Relations and Media Outreach:** Here's another great way to get yourself out there to get people excited about sbaMass! We need energetic people-persons to (1) Set up contacts with local media and provide press releases on our activities as needed and/or (2) Work on Spina Bifida and folic acid awareness. Evidence of ability to carry out these tasks from related experience is required.
- **Committee Chairpersons:** In an effort to be a more effective organization, we are focusing on committee work rather than having all projects handled at the Board level. A chairperson for our Adult Clinic Committee is a priority but all of our committees need development.

HELP US HELP YOUR FAMILY MEMBER WITH SPINA BIFIDA ANNUAL MEETING 10/1/07 Open to All Members

For more information and to view our strategic plan, please visit our website at: <http://www.sbaMass.org>. If you feel that you or someone you know can help, please contact us:

Ellen Dugan, Operations Associate
Tel: (888) 479-1900
Email: edugan@sbamass.org

Hyacinth M. Bellerose, Vice President
Tel: (978) 649-8724
Email: hbellerose@pblawoffices.com

Bits & Pieces

By Hyacinth Bellerose

- **Assistive Technology Exchange** www.getATstuff.com The Assistive Technology Exchange in Massachusetts is designed to facilitate simple, easy transactions between Massachusetts residents who can benefit from assistive technology devices and those who have assistive technology devices that are no longer needed.
- **The Family Center for Technology and Disability** www.fctd.info The Family Center is a resource designed to support organizations and programs that work with families of children and youth with disabilities. They offer a range of information and services on the subject of assistive technologies. Whether you're an organization, a parent, an educator, or an interested friend, they hope you'll find information that supports you in your efforts to bring the highest quality education to children with disabilities.



- The Liftvest (left) was a new product at conference that **enables caregivers to provide wheelchair users with safer, more comfortable transfers** www.liftvest.com
- **Coloplast has taken over Mentor.** So, if you are using Mentor products, you may see some changes coming up – at this point, the Mentor product labeling has not changed.
- Have you always wanted to go to **Arizona? Next year's SBA conference is in Tucson (June 22-25, 2008) and you can attend with a sbaMass scholarship.** Think about it now so you are ready to apply in the spring of 2008. Watch for a full article in our Fall newsletter.
- First-Ever Children's Book about Spina Bifida Available in English and Spanish; an Interactive E-Book (and printable), *Right Under My Nose* is designed to maximize discussion about the condition, its challenges and coping skills. See www.myspinabifidabook.org.
- AbilityPLUS provides thousands of disabled individuals and their families with lessons and the joy of inclusion in mainstream recreational activities in MA, NH and VT. Check out www.AbilityPlus.org for programs and some great testimonials.

“Being impulsive is not a bad thing if you learn to impulsively do the right thing!”

SBA urges women to follow the 1992 U.S. Public Health Service Folic acid recommendations

- Women who could become pregnant should take 400 mcg (micrograms) of folic acid through a vitamin. (This amount is also written as 0.4 mg (milligrams).)
- Women at increased risk for Spina Bifida (women who have a child or had a pregnancy affected by Spina Bifida or have Spina Bifida themselves) should take 4000 mcg (micrograms) of folic acid by prescription for 1 to three months before becoming pregnant. (This amount is also written as 4.0 mg (milligrams).) So, it's important for these women to plan any future pregnancy.

Please speak with your health care provider about folic acid today!

Come Join the YAG for the 3rd Annual Lunch and Learn!

Saturday, October 27, 2007 Wellesley Community Center, Wellesley, MA 10AM-3PM



- RSVP by October 20, 2007 to Ellen Dugan
- Don't Forget to RSVP Today!

Learn About:

- Ticket to Work and PASS Programs
- Emergency Preparedness
- National Service Inclusion Project

Guest Speakers:

- Resource Partnership
- Wellesley Police Department
- Institute for Community Inclusion

New!
For this event,
Teens and Adults
with Spina Bifida and
parents are invited to
attend!

Santa's Helpers Wanted!

The SBA of Massachusetts **Holiday Party** is fast approaching. Difficult to believe as we are still in the warm days of summer! If you are interested and available to help Santa shop for gifts, wrap, plan games or craft activities, please get in touch with Ellen Dugan, Operations Associate at edugan@sbaMass.org or (888) 479-1900.





WHEN I WAS A LITTLE KID, OF COURSE, I WAS BROWN ALL SUMMER. THAT'S BECAUSE I WAS FREE AS A BIRD - NOTHING TO DO BUT CATCH BUGS ALL DAY.
- ROY BLOUNT JR.





IT'S A SURE SIGN OF SUMMER
IF THE CHAIR GETS UP WHEN
YOU DO.

- WALTER WINCHELL



SUMMER AFTERNOON -
SUMMER AFTERNOON; TO ME
THOSE HAVE BEEN THE TWO
MOST BEAUTIFUL WORDS IN
THE ENGLISH LANGUAGE.

- HENRY JAMES

Membership and Benefit Information

Update your Membership Information Annually and receive a FREE GIFT.

The **OFFICIAL POSTING** and **MEMBERSHIP APPLICATION/UPDATE** are maintained on our website at www.sbaMass.org. For Questions or if you do not have internet access, provide your name, address, phone number, and your request (Membership Application/Update Package or Question) in a *phone message* to (888) 479-1900, by *email* to edugan@sbaMass.org or by *fax* to (978) 649-8725. Thank you for your cooperation so that we can better serve you!

sbaMass ANNUAL BENEFITS PROGRAM \$500.00 for 2007

A person with Spina Bifida (or that person's parent/guardian) who resides in Massachusetts or a New England state that does not have an SBA affiliated entity may apply for up to \$500 for calendar year 2007 by December 31, 2007.

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.

For the **OFFICIAL POSTING** and/or **APPLICATION** (both posted on www.sbaMass.org) and/or **Questions**, provide your name, address, phone number, email 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.

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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 SBA of Massachusetts 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!



- YAG Let's Talk, September 15th
- Annual Meeting, October 1st: All are welcome, Panera Bread Burlington, 7pm
- YAG 3rd Annual Lunch and Learn, October 27th
- SBA of Massachusetts Holiday Party, December 2nd

**October is
Spina Bifida Awareness Month!
Learn about our
Adopt-A-Ghost Program inside!**



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