

# sbaMass<sup>news</sup>

Spring 2007

The Newsletter of the Spina Bifida Association of Massachusetts

## Team sbaMass Runs Again!

Page 5

## Pressure Ulcers

Page 6

## CT Conference Report

Page 8

## Summer Picnic Announcement

Page 14

### *Also Inside*

Medical Research Corner  
Page 9

Youth and Adults Group Update  
Page 11

Kids Corner  
Page 12

**And More!**

## Beautiful Weather Again!

By Hyacinth Bellerose

The Third Annual SbaMass Golf Tournament was a success! With 93 golfers, just 2 more than last year, our net proceeds to sbaMass increased by over 50%! Our loyal golfers, generous sponsors and dedicated volunteers have made this year a true turning point. The golf tournament is no longer a struggling start-up fundraiser but, thanks to our supporters and volunteers, has become true money making and enjoyable event. Please enjoy the pictures of our special day. Pictures definitely do speak louder than words! If you missed the tournament this year, think about participating as a golfer, volunteer, sponsor or dinner attendee next year. After such a perfect day, all of us are already looking forward to the fun of next year's tournament.

Until next year...



**sbaMass**

**3 | 6**

**YEARS**

**1971-2007**









For more photos, see  
[www.sbaMass.org](http://www.sbaMass.org)



---

# Letter from the President

By Brian Packard

Thanks to all of you who helped to make the **3rd Annual SBA of Massachusetts Golf Tournament a great success.** The event was held at Sky Meadow Country Club on May 7th and once again received rave reviews from those attending. The day was filled with great golf and food, a terrific auction, a flyover of WWII airplanes and many laughs. **Hyacinth Bellerose and her committee did a terrific job continuing to expand this event, which has now become one of our key awareness and fundraising sources.**

I hope that many of you are now making your final plans to attend the SBA national conference June 24th-27th in Louisville, Kentucky. For those of you who have never had the opportunity to make it to conference, please do consider making the trip – it is well worth it. From the educational sessions and networking opportunities to Kids Camp, teen programming and social events, the conference has something for everyone. Those who have attended often say that it is the best learning and social experience they have had related to spina bifida. **Please also mark you calendars for the sbaMass Annual Summer Picnic, to be held at Danehy Park on July 21st.** Come reunite with friends, enjoy the great food and have some fun in the sun. This year, we will have a special treat for the kids, a visit from ZZ , who will be bringing many exotic animals that they can learn about and play with (see [www.xyz.com](http://www.xyz.com) for more information).

Toward the end of this busy summer, **Team sbaMass will run for the second time in the 35th Falmouth Road Race on Sunday, August 12th.** Because of our excellent fundraising and awareness-generating performance last year, the race organizers have granted us 25 charity entries into this year's event (10 more than last year), so we will likely raise significantly more donations this year. The team has already filled up quickly, but if you are interested in running with us, drop me an e-mail.

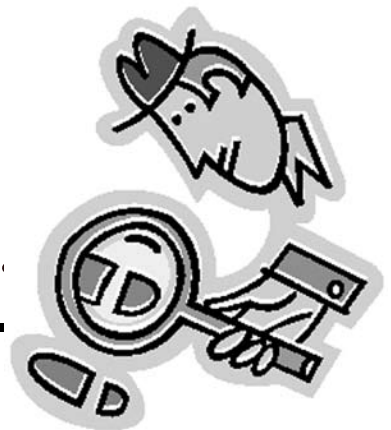
On the business side of things we have some good news to share. SBA has chosen our Massachusetts chapter to become their "test case" partner to develop an integrated website powered by Kintera, the leading web community provider for not-for-profits. This partnership will allow us to become the first chapter to share a common website look and feel with National, as well as provide us with powerful e-commerce and database capabilities. Stay tuned to see the new site live within a few months.

Best health and happiness to you all.

Brian Packard

## Come Join the Youth and Adults-Group for a Scavenger Hunt!

Saturday, June 9, 2007, 1-5 pm  
Burlington Mall  
83 Middlesex Turnpike  
Burlington, MA  
Route 128 (I-95) at Exit 32B  
Meet in Food Court, 2nd Floor



RSVP to Ellen Dugan  
at [edugan@sbaMass.org](mailto:edugan@sbaMass.org)  
or  
call (888) 479-1900

# Team sbaMass Returns to Falmouth Road Race!

By Brian Packard



Based on the great success our running team had in last year's Falmouth Road Race, the event's coordinators have invited us back to run the 35th Falmouth Road Race on Sunday, August 12th...this time with a much bigger team. Our 15 runners raised over \$25,000 in 2006, and this year we have been granted 25 charity entries! The fundraising and awareness our 2007 team will create should eclipse last year's. If you are on the Cape this summer, please come out to cheer us along the 7-mile course. We will, as always, be wearing shamelessly bright running singlets so you can spot us from a mile away. If you are interested in becoming a member of our official running team, please contact Brian Packard at [bpackard@sbaMass.org](mailto:bpackard@sbaMass.org).

## 5th Annual Sullivan Brother sbaMass Fundraiser at Beer Works

*Friday, August 10th, 2007*

**Boston Beer Works  
112 Canal Street  
Boston, MA 02114**

*Come support TEAM sbaMass as they prepare to run in the Falmouth Road Race!*

On Friday, August 10th Michael and Brendan Sullivan will be hosting their annual fundraiser at Boston Beer Works in support of sbaMass. Each of the past four years one of, or both, of the Sullivan brothers has run the Boston Marathon in support of sbaMass. This year, the challenge will be the Falmouth Road Race but the great night at Beer Works, and more importantly, the great cause the night supports will be the same.

Guests will be treated to complimentary appetizers, free pool, and the ability to bid in a silent auction of sports memorabilia, and other great prizes. In honor of Team sbaMass' run in the Falmouth Road Race, we kindly ask for a \$20 contribution at the door.

Thanks again for your support, and we look forward to seeing you in August!



---

# A Discussion of Pressure Ulcers

By Cathy Noonan

Skin care problems can be a major issue for anyone with a mobility or sensation loss, such as spina bifida. Pressure ulcers (also known as “decubitus ulcers” or “bedsores”), skin tears, and skin fold problems can be quite troublesome. This article will deal specifically with pressure ulcers. Good preventative care is essential, and proper treatment and follow-up of pressure ulcers can aid in the healing process.

## Causes

My patients with pressure ulcers often ask how the ulcer happened. Too much pressure between a bony area (like the heel, hip or pelvis) and a hard surface (like shoes, a mattress, or a wheelchair) causes a lack of blood flow to the skin and tissues. Lack of blood flow results in a lack of oxygen and nutrients, and the tissues become damaged or die (necrosis). Usually, the skin shows evidence of pressure by becoming red or purple (this can be difficult to see in people with darker skin tones). But other times, the effects of pressure may take time to be seen, as the pressure may first occur in the tissue against the bone, and the skin is the last place to show injury. The latter explains why suddenly appearing ulcers can be quite severe and deep - the injury was already done before the skin changed color. Ill-fitting braces, improperly fit wheelchairs, poorly fitting shoes, lack of body movement, and improperly inflated wheelchair cushions can all cause pressure. Any area that has decreased sensation is a high-risk area. In a person without loss of sensation, the lack of blood supply to a tissue or skin area will signal the person to shift position or to move. In people with Spina Bifida, depending on the level and type of involvement, this signal may not occur. Thus, extra care and attention is needed to prevent pressure in a sensation impaired area.

Scoliosis can sometimes be a contributing culprit, as it shifts the sitting surface, and causes more pressure on one buttock more so than the other. Also, poorly fitting wheelchairs may not help keep an even sitting surface, and may cause more weight on one side of the buttock/hip/sacrum (tailbone) than the other.

It is a common belief that pressure ulcers do not occur in children. Not true! Any person of any age is at risk if there is a mobility or sensation loss! It is true, however, that the risk increases as one becomes an adult.

## Prevention

Prevention strategies differ according to age. Unfortunately, even with excellent preventative care, pressure ulcers can still occur. Skin care is a lifelong issue for people with Spina Bifida, and independence with self-assessment should be encouraged. Children in the early years should learn

the strategy of weight shifting and may need reminders. Schoolteachers and aides can assist with this. Older children may benefit from a timer as a reminder to weight shift. Weight should be shifted off a bony area (for example, shift weight from one buttock to the other while in the chair) every 15 minutes, with overall position changes every 1-2 hours. Remembering to shift weight or move so frequently can be a burden, but the outcome (no pressure injury) will be worth it! Friction, or dragging pressure on the skin, can cause skin injury and increase the risk of pressure ulcer development. You should lift, rather than drag, their bodies when moving from place to place.

Be aware of a danger signal-a red or purplish area that develops after prolonged pressure on an area. This is a sign that the skin and the tissue underneath is being damaged-pressure relief in this area is needed! A red or purplish area that takes more than a few minutes to go away once the pressure is removed is an extra urgent danger signal.

Daily skin checks are needed, and a mirror or someone's help may be required. The skin check should be part of a daily routine. Pressure ulcers usually develop in bony areas, so close attention should be paid to elbows, hips, buttocks, sacrum (tailbone), ankles, heels, and feet. Early recognition and treatment of a problem skin area can help prevent development of major problems such as infection or draining wounds.

Maintaining a good bowel and bladder program can also prevent pressure ulcers. Wet skin can break down more easily. Diaper edges that are too tight can cause skin breakdown. Prolonged toilet sitting for bowel movements is another problem, and the unpadded toilet seat can be a source of excessive pressure. Your health care team can help address these issues.

Properly fitting shoes are very important even for people who do not walk. There can be pressure on all sides of the foot from the shoe, particularly in the heel area (if in a wheelchair) or on the surface that touches the floor (if walking or using crutches). Legs and feet can often become swollen (also known as edema) while in the wheelchair, and this can cause the shoes to be too tight. Feet should be examined for any red spots upon shoe removal. Red or purplish spots are signs of pressure, and the shoes should be adjusted. Calluses are evidence of chronic irritation and should be addressed. Continued pressure on an injured area can lead to severe tissue breakdown.

Keeping weight steady also helps keep skin healthy. Excessive weight often contributes to skin issues, due

---

to decreased blood circulation, increased pressure and decreased movement. A good diet and good hydration gives skin the nutrients it needs to stay healthy and heal areas that are injured. Being too thin can result in lack of fatty padding over the bony areas, and should be avoided as well. Daily exercise and a healthy lifestyle will promote good skin as well. Smoking can decrease blood circulation to skin and should be avoided.

Wheelchairs, pads and other equipment should be evaluated yearly for fit. Plan ahead! It can take several months to obtain insurance authorization for any required products or equipment.

### **Treatment**

Obviously, prevention is better than ulcer treatment! But if a pressure area does develop, pressure relief and care of the open area are important. Pressure relief usually means time out of the wheelchair, or off the feet. Patients who are spending a lot of time in bed to keep pressure off an area may want a special pressure reduction mattress overlay to help prevent other pressure ulcers from developing. This requires a prescription which can be obtained from a health care provider. Most medical supply companies carry them. Other support surfaces include padded shower chairs. Pillows can be used while in bed to keep bony areas from touching each other (such as the knees or ankles). Pillows should not be used as wheelchair cushions.

If a pressure ulcer wound is present, you/your child should see a health care provider for assessment and treatment recommendations. There are many wound care products available, and a health care provider can help determine which products are best. The usual goals are wound healing and drainage control. Sometimes the assistance of a plastic surgeon may be needed. A physical therapist can be helpful in evaluating a wheelchair or braces. Sometimes extra padding or cushioning is needed to keep pressure off an area. "Doughnuts" should not be used as seating cushions because they increase pressure over the area of contact and may actually cause pressure ulcers. In some cases, particularly with chronic pressure ulcers, some of the bony prominence may need to be surgically removed to decrease pressure and promote wound healing. A podiatrist can be helpful with shoe fitting and with orthotics, which can help distribute foot weight better.

There are financial costs related to pressure ulcer. Parents may need time off from work for medical appointments or home nursing visits for treatment of their child's wound. For older patients, needing to keep pressure off a sitting area

can result in time away from school and/or work. Wound care products can be costly if not covered by insurance. If the ulcers are severe enough, hospitalization, surgery, and/or a rehabilitation stay could be required. Quality of life, particularly if the ulcer area is large, visible, or draining, can be altered. Surgery may be needed if the ulcer is very big or deep, or will not heal. The most common surgical procedures are flap procedures, where tissue is moved from one spot to another to fill in the open area. A patient will need bedrest and complete pressure relief for several weeks after this procedure. The area may have increased susceptibility to pressure injury again.

In summary, pressure ulcers can occur in anyone with a sensation or mobility impairment, and can be costly and time-consuming to treat. Frequent position changes and proper assistive equipment can help decrease their occurrence. Any pressure area should be addressed quickly to decrease the risk of a worsening problem.

**Cathy Noonan, RN, MS, CPNP is a Pediatric Nurse Practitioner at Children's Hospital, Boston. She can be emailed at [Catherine.noonan@childrens.harvard.edu](mailto:Catherine.noonan@childrens.harvard.edu).**

---

### **Bike Available!**



The bike is in good condition. It is fun to pedal on mostly flat ground - a bit difficult on an incline. There is a velcro seat belt and a helmet. The seat is 25" from the ground. There are foot pedals. The bike measures 21" from the edge of seat (behind your knees when sitting) to toe of foot pedal. It measures 34" from top of the back of seat to extended handlebar. It is 26" wide. It measures 41" from handlebar to ground. It's fine for people to contact me directly with questions either by email ([milo@socialnet.com](mailto:milo@socialnet.com)) or by phone 978-256-1024.

# A Little Road Trip

By Matt Neal

**Saturday morning,  
March 24, 2007, 7:30 am.**



Grace (age 6) and I are up and about (typical Saturday morning hours for Grace, not so much for me). My daughter and I are about to hit the road. We're taking a little trip down to Hartford CT to check out the '3rd Annual Educational Conference on Spina Bifida & Kids' Camp' put on by our esteemed sister chapter, the Spina Bifida Association of Connecticut. It starts at 9am and it's about an hour and a half drive from our house, so we'd better get a move on.

We're a bit late, of course, but it's a really nice ride down. Grace is old enough to enjoy some of the 70's tunes I put on the CD, but not old enough to know how truly out of step with the musical times I am. Things go well and it looks like we won't be more than a few minutes late until I get lost in the middle of Hartford (curse you, Mapquest).

Finally we arrive at the University of Hartford Magnet School. It's a beautiful new elementary school and extremely accessible. I've pretty much missed the first session, but there are three more for me to attend and the kids' camp is still in the 'free play' portion. So, after a short stop in the very accessible and kid-friendly bathroom, we walk down the hall to the kids' camp. Grace is not what you'd call a shy kid, so within five minutes or so she has met a couple of the adult volunteers and some kids – and I have become superfluous. It's time for me to join the adults.

The conference consists of four sessions, each with four presentations going on simultaneously. Out of those sixteen talks, I attended a talk on Assistive Technology and two on Nonverbal Learning Disorder (and missed the Session I talk on Sensory Integration). I learned a lot. There were about a dozen people in each of the

talks I attended, and I understand the total attendance was about 120. The rest of the program included a wide variety of topics from 'Preparing Your Child for Surgery' to 'Sexual and Reproductive Health Issues in Spina Bifida'. In other words, the SBA of CT did a great job putting together a diverse, interesting, and useful program. And it only cost \$15.

Grace had a great day too. She was delighted to see her friend Elaina Cardenas of Sturbridge, plus she made some new friends as well. Then the 'Tails of Joy' dog therapy group came in to visit the kids. All in all, it was a pretty full day.

Keep this event in mind for next year. It's a great event in a nice venue, easy to get to and not very expensive. The Connecticut chapter is investing a lot of time and energy into putting on this event and we are fortunate to be able to take advantage of that.



My favorite SBAofMA'er spends some time with one of the 'Tails of Joy' therapy dogs at the 2007 Connecticut Educational Conference on Spina Bifida Kids' Camp

***Did you take your folic acid today? If every woman  
between the ages of 15 and 44 were to  
take 400mcg of folic acid every day,  
the incidence of spina bifida would be reduced by up to 70%!***



---

# Medical Research Corner

By Ginny Briggs

Most people with spina bifida (s.b.) use assistive devices such as wheelchairs, crutches and braces to help them get through daily life. Using something that fits well, is comfortable and works well in the daily environment can make a significant difference in the success and happiness of someone with s.b. However, these devices were initially designed purely for mobility rather than for comfort or for fitting into society. Wheelchairs were a great invention, but how many doorways and bathrooms are wide enough to accommodate them? Many people with disabilities, and particularly people with spina bifida, also deal with changes in their physical abilities throughout their lifetimes. These changes occur from cord-tethering, muscle weakness, excessive weight gain or just normal growth changes. Many kids who start out on crutches transition to wheelchairs before age 5. Some people, both adults and kids, move back and forth between wheelchairs and crutches on a daily basis, depending on where they are and how they feel. The development of these assistive devices has been a great success, enabling people with physical abilities to become more mobile. However, going to college, going to public places like restaurants or holding down a job generally require more than just mobility for success. For example, the services available to s.b. children while they are in public schools are significantly better than what is available in the typical work environment for s.b. adults. In a recent study done at the University of Washington in Seattle, this issue was examined in a group of young adults with spina bifida.

The study consisted of 348 people with s.b., aged 13 to 27 years old. Though the majority of people reported using either wheelchairs (57%), braces (35%) or crutches (23%), only about a third of the entire group said they were able to participate in activities outside the home. So, though most people with s.b. are using some sort of assistive device to help them get around, it may not be helping them get jobs, go to school or make friends. It is encouraging that the study also found that personal care independence (eating, washing and dressing without help) increased with age. In fact, the majority of people reported a moderate to high level of independence in

these areas. This type of self-care success will help prepare an individual for life in society, but other issues related to physical disabilities may likely have important impact on how well someone can do. For the s.b. community, both physical and learning disabilities can be problematic when trying to function in a public setting. Fortunately, great strides have been taken in the design of better wheelchairs, that are lighter weight, more portable and easier to maneuver. Crutches and braces have also evolved into much lighter weight and more comfortable walking aids. This technology will certainly help one cope with the challenges of public transit, elevators and restrooms, for example. For people with learning disabilities, there are a number of software programs to help students with reading, writing and other subjects. As these aids become more and more available, both kids and adults with s.b. will be able to feel more comfortable exploring the world outside their homes and schools. Though progress has been made in helping people with physical disabilities adapt to an able-bodied world, there is still a significant number of people with s.b. who are having difficulty with the transition. With a growing number of s.b. people living healthy lives well into adulthood, it is important to focus on helping them make that transition. Once a person finds they are mobile enough to venture outside the safety of their home, they may find a number of unexpected obstacles, and it will take a combination of community support and new technology to overcome them.

*Reference: Johnson KL, Dudgeon B, Kuehn C, Walker W. Assistive technology use among adolescents and young adults with spina bifida. American Journal of Public Health. 2007 Feb;97(2):330-6.*

---

***sbaMass***

***Promoting the prevention of  
Spina Bifida and enhancing the  
lives of all affected***

---

# Bits & Pieces

By Hyacinth Bellerose

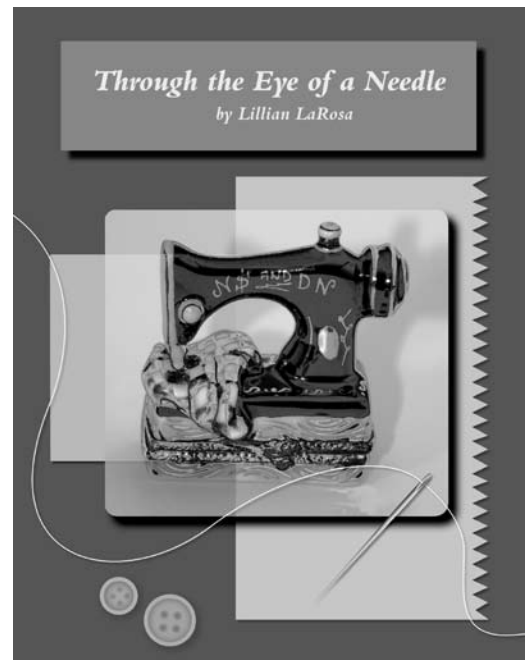
A few useful websites related to education, internships and careers:

- **HEATH Resources Center:** A national clearinghouse on post secondary education for students with disabilities. Includes information on educational support services, policies, procedures, adaptations and opportunities at American campuses. **[www.heath.gwu.edu](http://www.heath.gwu.edu)**
- **NCSET:** The National Center on Secondary Education and Transition, offers technical assistance and disseminates information about transition options for youth with disabilities. **[www.ncset.org](http://www.ncset.org)**
- **ENTRY POINT:** A program of the American Association of the Advancement of Science (AAAS) offers paid 10 week internships and semester co-ops in major companies throughout the US to students with disabilities. **[www.entriypoint.org](http://www.entriypoint.org)**
- **Career Opportunities for Students with Disabilities:** Bridging the gap between career services, disability services and employers for students with disabilities. **[www.cosdonline.org](http://www.cosdonline.org)**
- **The Ethel Louise Armstrong (ELA) Foundation Grant:** Grant funds for programs in the areas of arts, advocacy and education to nonprofit organizations which are led by or support adults with disabilities (over 22 years old). Grants from the ELA Foundation range from \$1,000-\$5,000. For more information, visit **[www.ela.org/grants/grants.html](http://www.ela.org/grants/grants.html)**.
- **SUMMER** is almost here and it's not too early to think about Summer Camps. Check out our listings under Summer Camps and Ongoing Programs under "Links" at **[www.sbaMass.org](http://www.sbaMass.org)**. Please let us know if you have any camps or programs to add to the list or if you have any comments regarding camps you or your child has attended. For a great example of ongoing programs, check out **[www.nepassage.org](http://www.nepassage.org)**: Northeast Passage delivers disability-related health promotion and adapted sports programs throughout New England. Northeast Passage is a program of the University of New Hampshire's School of Health and Human Services and is an affiliate of Disabled Sports USA. Wheelchair rugby anyone??? Kayaking??
- **Right Under My Nose** an online story book for kids with spina bifida. Offering kid-friendly, no-nonsense online activities and ways for parents to talk to their kids about sb, this book was developed by U of So California and Children's Hospital LA and has a Spanish version as well. Check it out at: **[www.MySpinaBifidaBook.org](http://www.MySpinaBifidaBook.org)**.

## Thank you!

By Brian Packard

The sba of Mass. would like to extend our sincere thanks to Lillian La Rosa for her generosity to our organization. At the age of 98, Lillian published her 4th book, titled *Through the Eye of a Needle*. She has decided to donate the proceeds from sales of the book to sba of Mass, and already donations have totaled over \$1,100! In a recent conversation with Lillian, I was given many pearls of her wisdom, including my favorite: "You are never too old to give back to people." Thank you Lillian for your sage advice and generous gifts.



The book is now available for \$10 from the Brown Publishing Network. Give them a call at (781) 547-7600



---

# Youth and Adults Group Update – Back in Full Swing!

By Jen Kuhar

Now that Spring is upon us, the sbaMass Youth and Adults Group is back in full swing. On Saturday, April 21, 2007, we gathered at Children's Hospital Boston for an informative, interactive discussion about Dating and Relationships that was led by Pixie Plummer, MD. The discussion focused around important issues such as how to bring up this topic to our physicians, accessibility issues for women's annual exams, where to meet people, and communication, particularly in the area of when it is appropriate to open up about spina bifida and how it can affect our intimate relationships. Pixie stressed the importance of finding someone in our lives to whom we comfortable asking these important questions. Maintaining healthy relationships is an important part of one's overall health and this topic will certainly be discussed again in the future. Thank you to all who participated.

Don't miss the Scavenger Hunt taking place on Saturday, June 9th at 1:00PM. We will meet in the Burlington Mall Food Court on the second floor. The afternoon is sure to be filled with lots of fun and surprises. On Saturday, September 15th, we will return to the Cary Memorial Library in Lexington. Details for this day are still being worked out. Watch for details during the upcoming months.

The Annual Lunch and Learn, our main educational event of the year, will take place on Saturday, October 27th at the Wellesley Community Center in Wellesley. This year, in order to reach more folks, in addition to adults with spina bifida, teens and parents will be invited to participate. We hope this facilitates information sharing among all groups. Mark your calendars now, as you will not want miss out on this day! If there is a topic that you would be interested in discussing, please email your suggestions to Ellen Dugan at [edugan@sbamass.org](mailto:edugan@sbamass.org), or leave her a message by calling 888-479-1900.

We hope that you are as excited as we are about the upcoming events and as always, we welcome your suggestions as to how we can improve. Got an idea? Just let us know by contacting Ellen Dugan (contact information above). We look forward to seeing 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.

- sbaMass was recently notified that we will be given 25 numbers in the Falmouth Road Race for our fundraising efforts.
- We continue our folic acid outreach efforts. sbaMass attended a Bridal Expo in Foxboro in

February where we handed information out to over 200 people. We also continue to reach out to local OBGYN practices, encouraging them to distribute folic acid information to their patients.

- The Summer Picnic will be July 21, 2007 at the beautiful Danehy Park in Cambridge, MA. Stay tuned for more information.
- The Board continues to work to meet the new minimum requirements outlined by SBA and IRS. The sbaMass website will be redesigned in the upcoming months.



## SPRING SUMMER WORD SEARCH

Y	H	W	V	U	R	A	A	S	K	H	C	B	Z	G
Z	A	I	P	E	N	S	A	Z	G	F	I	E	Q	E
X	S	U	M	I	Y	N	L	E	O	T	N	A	U	W
C	G	M	M	X	D	Q	R	E	G	H	C	C	W	C
W	U	A	V	D	R	G	W	Y	R	A	I	H	C	R
S	L	R	V	T	U	L	S	S	F	R	P	E	J	A
S	E	I	L	F	R	E	T	T	U	B	I	S	N	N
Y	A	S	L	D	D	D	G	I	K	G	T	U	L	T
O	S	L	A	D	N	A	S	N	N	B	M	A	Q	S
N	U	O	B	Z	N	A	I	I	I	E	C	S	I	S
A	I	T	E	S	N	J	M	S	T	R	L	R	D	P
J	Q	H	S	J	O	M	T	E	Y	N	P	G	P	Z
B	W	H	A	I	I	F	L	O	W	E	R	S	Q	E
L	Y	S	B	W	D	Y	J	S	P	O	R	T	S	T
V	H	I	S	Y	G	E	K	M	J	O	B	Z	Y	Z

ANIMALS  
ANTS  
BASEBALL  
BEACHES  
BUTTERFLIES  
DAISY  
FLOWERS  
OUTSIDE  
PICNIC  
SAND  
SANDALS  
SPORTS  
SPRING  
SQUIRRELS  
SUMMER



Q. What season is it when you are on a trampoline?

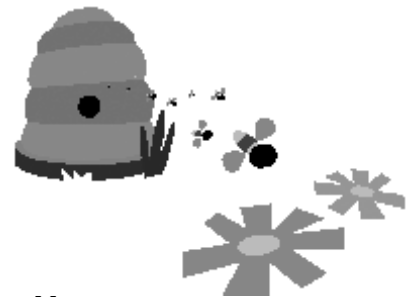
Q. When do monkey's fall from the sky?

Q. Can February March?

Q. What flowers grow on faces?

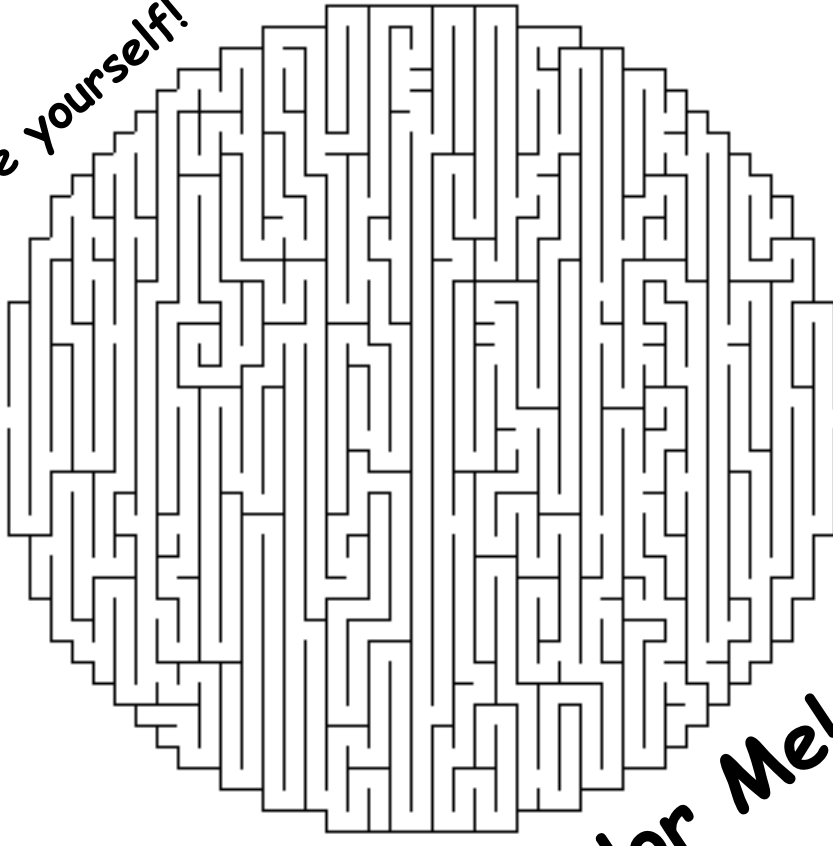
Q. Why is the letter A like a flower?

Answers on next page!



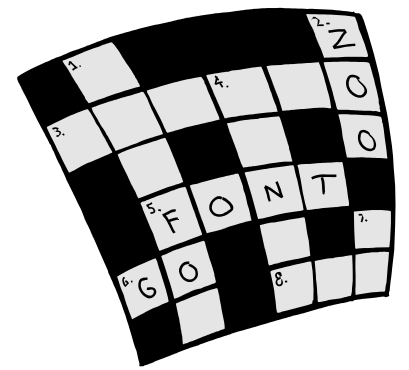


Amaze Yourself!

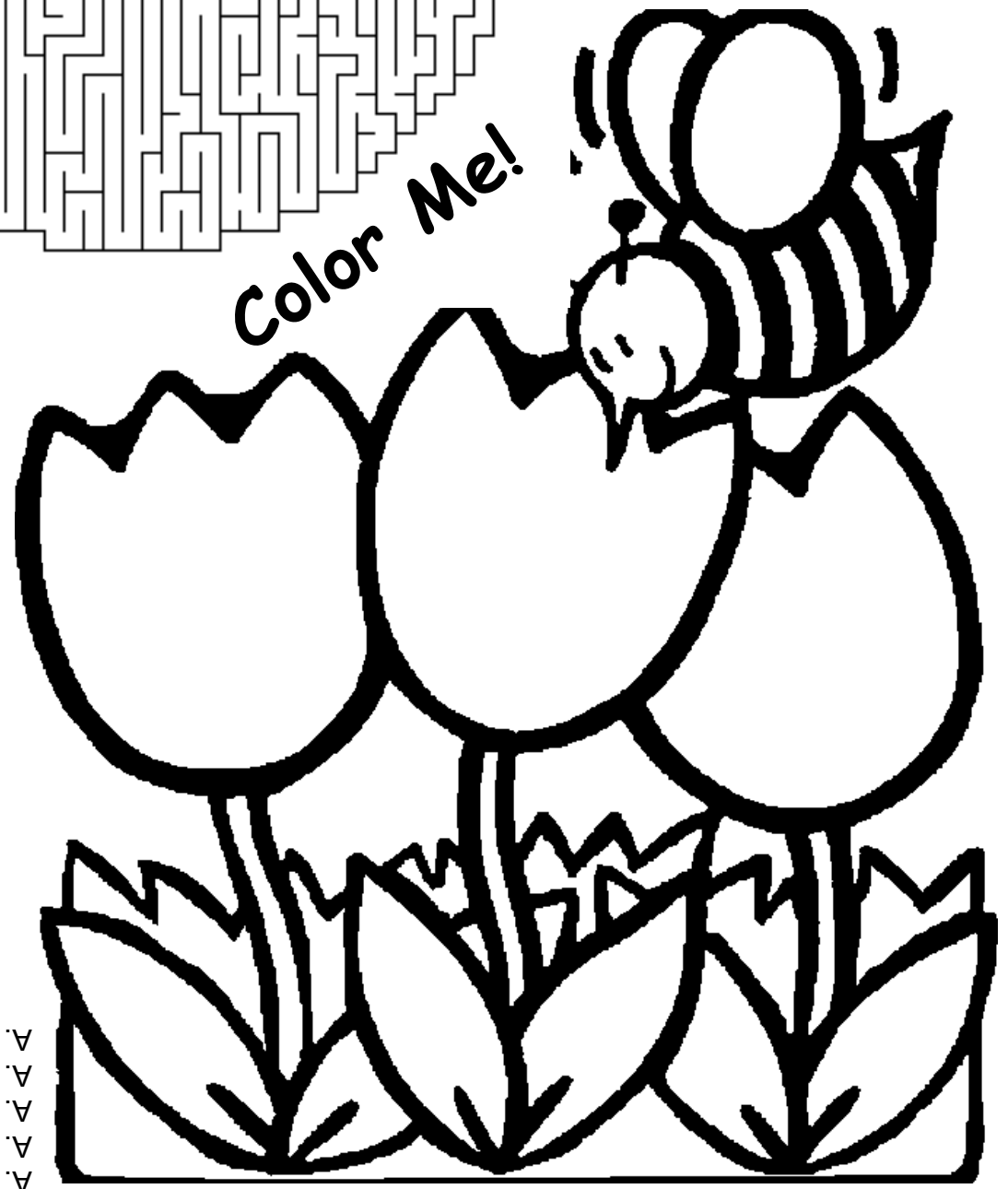


Start Here

End Here



Color Me!



A. Spring Time!  
 A. During Ape-ri! showers!  
 A. No, but April May!  
 A. Tulips (Two-lips)!  
 A. A bee (B) comes after it!

MARK YOUR CALENDARS FOR THE  
**FIFTH ANNUAL**  
**SBAMASS SUMMER PICNIC**

**SATURDAY, JULY 21, 2007**

**12:30 PM - 4:30 PM**

**AT DANEHY PARK**

**(\*\* ENTRANCE AT 99 SHERMAN STREET, NOT MAIN ENTRANCE \*\*)**

**CAMBRIDGE, MA**

**PARKING LOT AND PICNIC AREA  
NEAR THE OFFICE & RESTROOMS**



**MAP AND DIRECTIONS ON THE NEXT PAGE**

- ***Food and Beverages:*** Lunch will be provided.
- ***Please bring*** sunscreen and a lawn chair (if you prefer a chair to the grass!).
- ***Picnic Fun:*** Activities and surprises for all ages.
- ***Other activities*** at Danehy Park include a water spray park, playground, and numerous sports fields.



**\*\*\*\* PLEASE RSVP \*\*\*\***

If you know ahead of time that you will be attending, please let us know how many people you expect to bring with you, for planning purposes. Please RSVP to Ellen Dugan at [edugan@sbaMass.org](mailto:edugan@sbaMass.org) or to the sbaMass Voice Mail (888-479-1900). If your plans change last minute and you did not RSVP, feel free to join us anyway.

**BY PHONE: 888-479-1900 OR ONLINE AT [www.sbaMass.org](http://www.sbaMass.org).**



# DIRECTIONS TO sbaMass PICNIC:

## DANEHY PARK SHERMAN STREET ENTRANCE

(99 SHERMAN ST, CAMBRIDGE, MA 02140)

**Please note:** There are lots of different ways to get to Danehy Park, but if you don't know the area, we suggest you use the directions from 95/128. They might be slightly longer than some others, but they are the least confusing!

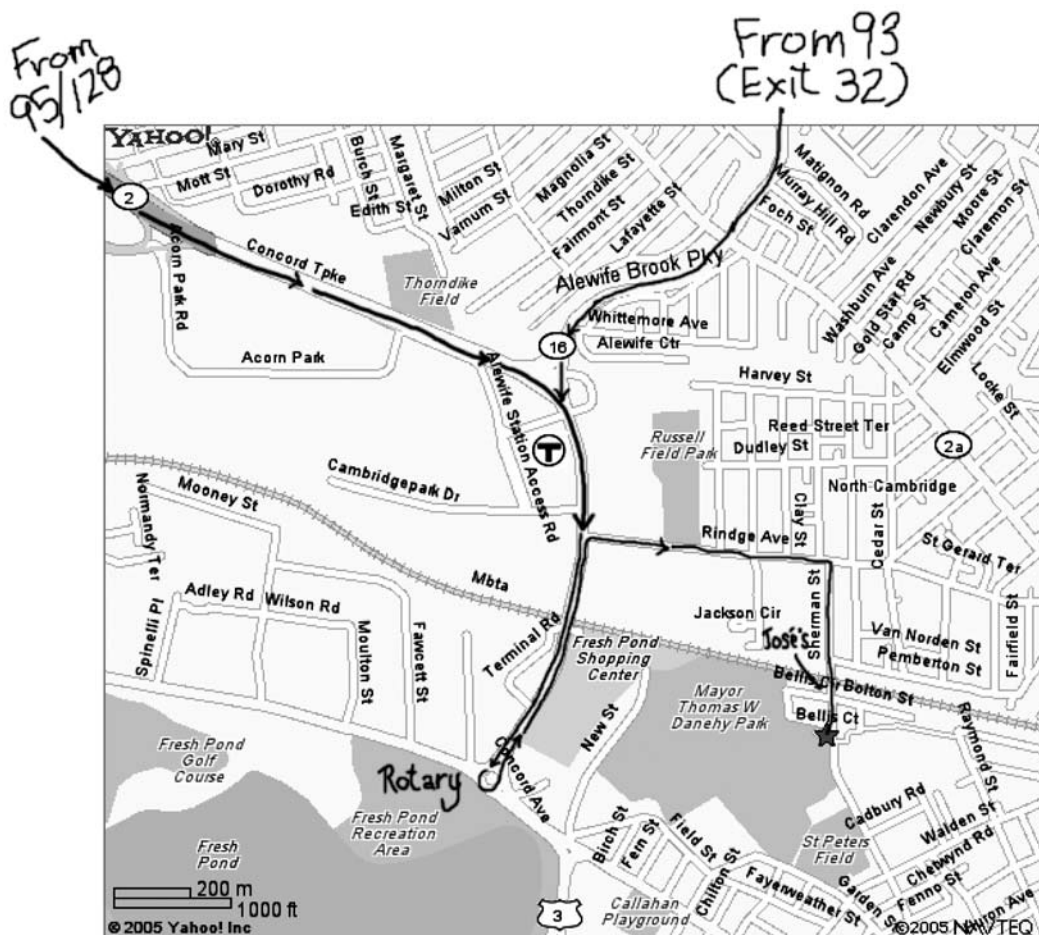
### From Route 95/Route 128 North OR South:

Take Route 2 EAST until it ends/splits. Stay right at this split. You'll see the Alewife (Red Line) T station on your right. Drive past the T station, then follow directions below \*\*.

### From Route 93 North OR South:

Take Exit 32 (Medford Square) and follow signs to Route 16 WEST – a long, winding stretch of road that changes its street name a couple of times. Don't be thrown by that. Stay on Route 16 until you reach its intersection with Route 2 at the Alewife T Station - a total of about 2.5 miles. When you see the T station in front of you, curve left, keeping the T station on your right. Then, follow directions below \*\*.

\*\*You will pass over a railroad bridge and see the Fresh Pond Mall on your left. Keep driving past the Mall to the first rotary (at the Tin Alley Grill). Take the rotary all the way around, and drive *back* – toward Alewife Station and past the Mall again. Go *back* over the railroad bridge, and make an immediate right hand turn onto Rindge Ave. Continue on Rindge Ave for a few blocks, past a cemetery on your right, then turn right on Sherman St. Drive over the railroad tracks and past José's Mexican Restaurant on your right. About 1/10 mile beyond José's is the Danehy Park parking lot on your right. If the lot fills up, there is another lot a little further along Sherman, at a baseball field.



---

# sbaMass Kids Dance for a Great Cause!

By Brian Packard

Two North Andover members of sbaMass recently performed in front of more than 500 people as part of the St. Jude's Performance Team. 11-year old Julia and 8-year old Katie were part of a 52-member hip-hop dance team that performed at matinee and formal evening dinner/auctions in Andover on March 3rd at the Wyndham. The event, highlighted by the dance team's pulse-pounding moves, raised over \$85,000 for the famous St. Jude Children's Research Hospital. While St. Jude's hosts fundraising events around the world, this performance team is the only one of its kind and has raised well over half a million dollars since its beginning several years ago. Katie and Julie were both extremely proud to be able to give back to a great cause and help kids like



Katie (left) and Julie perform!

## Mark Your Calendars!



- ✦ Youth and Adults Group  
Scavenger Hunt  
June 9th, 11 pm Burlington Mall
- ✦ 5th Annual Summer Picnic  
July 21st, Danehy Park
- ✦ Falmouth Road Race  
August 21st
- ✦ Youth and Adults Group Event TBA  
September 15th, Cary Memorial  
Library, Lexington
- ✦ Youth and Adults Group  
Lunch & Learn  
October 27th, Wellesley Community  
Center
- ✦ Christmas Party  
December 2nd

**Donate Now!**

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

Simply visit  
**[www.sbaMass.org](http://www.sbaMass.org)**  
and  
click on the  
Contribute link

---

# 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](http://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](mailto: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

---

# **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 [edugan@sbaMass.org](mailto:edugan@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](http://www.sbaMass.org) for ongoing events and programs.

***Please remember to fill out the enclosed form to update your membership! Simply fill it out, fold, tape, add a stamp and drop it in the mail.  
Thanks!***



# Contacts

**sbaMass Telephone**  
sbaMass Fax

**888-479-1900**  
978-649-8725

**SBA Telephone**

**800-621-3141**

## sbaMass Officers

### **President**

**Brian Packard**

Email: bpackard@sbaMass.org

### **Vice President**

**Hyacinth Bellerose**

Email: hbellerose@sbaMass.org

### **Treasurer**

**Brendan Sullivan**

Email: bsullivan@sbaMass.org

### **Clerk**

**Jennifer Kuhar**

Email: jkuhar@sbaMass.org

## Board of Directors

### **Matt Neal**

Email: mneal@sbaMass.org

### **Ginny Briggs**

Email: gbriggs@sbaMass.org

### **Peter Jablonski**

Email: pjablonski@sbaMass.org

### **Joyce Hillis**

Email: jhillis@sbaMass.org

## Operations

### **Ellen Dugan**

Email: edugan@sbaMass.org

888-479-1900

## sbaMass Regional Representatives

### **Southeastern Massachusetts**

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@sbaMass.org

### **Canister Collections**

Ellen Dugan

Email: edugan@sbaMass.org

### **Fundraising**

Hyacinth Bellerose

Email: hbellerose@sbaMass.org

### **Literature and Lending Library**

Danielle Everett

781-826-4485

### **Medical Issues**

Ginny Briggs

Email: gbriggs@sbaMass.org

### **Membership**

Matt Neal

Email: mneal@sbaMass.org

### **Memorial Donations**

733 Turnpike Street, #282

888-479-1900

North, Andover MA 01845

### **Parents Helping Parents**

Cara Packard

Email: cpackard@sbaMass.org

### **Public Awareness / Publicity**

Ly Weintraub

E-mail: ly@limetartan.com

### **Youth & Adults Group**

Jen Kuhar

Email: jkuhar@sbaMass.org

**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 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  
for making the  
2007 sbaMass Golf Tournament a Success!**

**Major Sponsors**

John Phillips  
Kaite Packard's Family and Friends  
Verano Inc.  
PGA Deutsche Bank Championship  
McKenna Builders Inc.  
The Balliro Family  
Allied Waste Industries  
Air Tran

**Contest Sponsors**

Smith Motor Sales  
Hyacinth E. McKenna

Please visit [www.sbaMass.org](http://www.sbaMass.org) for links to our full list of sponsors.



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

Toll Free Phone: (888) 479-1900

Web site: [www.sbaMass.org](http://www.sbaMass.org)

NONPROFIT ORG  
US POSTAGE PAID  
DUNSTABLE MA  
PERMIT NO. 20