sbaMass news

Spring 2008 The Newsletter of the Spina Bifida Association of Massachusetts

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Letter from the President

by Brendan Sullivan

Since we last spoke, the Spina Bifida Association of Massachusetts (sbaMass) experienced two significant gains in both human and financial resources. First, and most importantly, the Board welcomed two new Directors to its table. Joining the Board are Cara Packard and Kathleen Pease. Cara is very familiar with sbaMass as her husband, Brian, is our past president. As the mother of a child with Spina Bifida, Cara brings a wealth of professional skills and also personal experience with Spina Bifida. As a medical professional, Kathleen brings with her enormous knowledge from the medical field as well as personal understanding of Spina Bifida gained from a family member's experience. Given the skills of each of these individuals and their tireless work ethic, the Board is grateful to them for choosing to serve sbaMass in their new capacities. Congratulations and thank you Cara and Kathleen!

Secondly, I have the pleasure of announcing another significant contribution to sbaMass. In December, CIBC, a leading North American financial institution, selected sbaMass as a participant in its Miracle Day program at the request of Mr. Adam Lawrence, a close friend of the Packard family and a friend of sbaMass. On a chosen day, CIBC's sales and trading staff donated all of their fees and commissions to charities. This past month, sbaMass was informed that our share in this annual event will be a $15,000 donation! This generous gift will allow sbaMass to enhance its programs and benefits in the coming year. We are most grateful to CIBC and Mr. Lawrence for their substantial generosity to sbaMass!

This quarter's newsletter contains information about many upcoming local events. Important items include information about our annual Summer Picnic, the Jean Driscoll Scholarship, the annual Golf Tournament, and our benefits program for the Annual SBA Conference. This year's conference is in Phoenix, Arizona in late June. I encourage you to consider applying for our special scholarship program that enhances annual benefits so you may attend the SBA Conference. It is an informative, fun event for adults with spina bifida, parents, and children so I hope you consider making the journey. You will learn much about Spina Bifida, the efforts of SBA on behalf of its members and I guarantee you will also have some fun.

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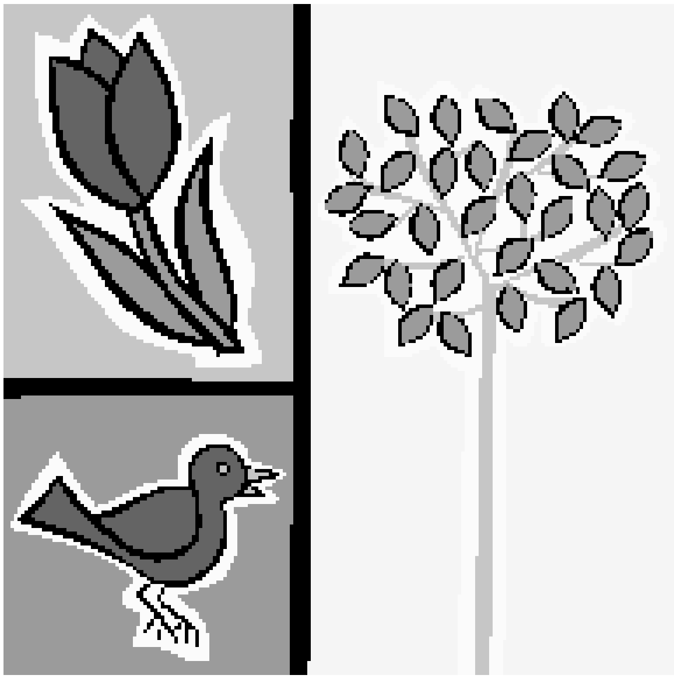
Letter from the President

continued from page 1

As winter turns to spring, I wish you great health and a warm spring season! I look forward to seeing you at many of our upcoming events. Enjoy the news!



Thank You!

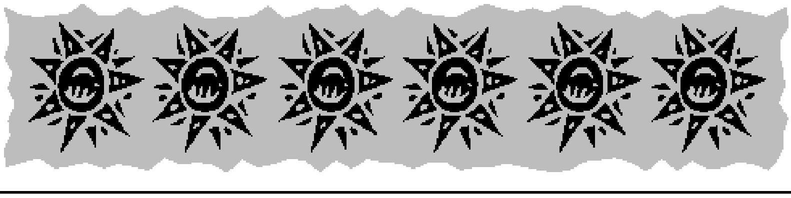
The Board of Director's of the Spina Bifida Association of Massachusetts would like to thank Susan and Anthony Leo of Peabody and their customers for their ongoing commitment to sbaMass. For the past several years Susan and Anthony have placed a canister at the register of their superette T-Stop in Lynn, MA, collecting donations for sbaMass. This year their generous customers donated $500 to support the programs and services provided by sbaMass.

Adult Spina Bifida Clinic Committee Needs Your Help!

by Ginny Briggs

It is becoming increasingly clear that one of the most important projects sbaMass will be involved, in the coming years, in the formation of an adult Spina Bifida (SB) clinic in Boston. As kids reach adulthood, the demand for appropriate adult medicine services will only grow. The sbaMass has recognized this as a priority for all our members as well as others living with SB in Massachusetts and the other New England states we serve. As a result of this realization, planning stages have begun to organize a committee dedicated to opening a clinic for adults with SB. The first meeting to discuss this took place in January, 2008. It is evident that there are many tasks to be done to succeed. While the clinic we envision is a real possibility, it will take many hands and much time to make it a reality.

The small committee we have now consists of dedicated, hard-working people. However, the committee is in need of more help to be able to effectively complete all the tasks needed to make this happen. The more committee members we have, the faster we will reach our goal. If you or someone you know is interested in joining our committee, please e-mail Ginny Briggs at **gbriggs@sbaMass.org**.



Bits & Pieces

by Hyacinth Bellerose

PROVIDING MEDICAL UPDATES: We all have well meaning and truly concerned family and friends that want and need to know updates on medical issues, especially for surgeries and other emergency situations. Given the constant ups and downs of medical issues, the extra hands on time you need during medical situations and other basic obstacles that do not allow you to call everyone you know with regular updates, communication can be quite frustrating for all parties.

One suggestion is updating your outgoing home answering machine or cell phone message at set intervals providing an update that your friends and family can check. This may raise privacy issues regarding people calling you that do not want or need an update, but it is a quick resource available to most people.

At the end of a medically involved winter last year, someone mentioned CarePages to us – **www.carepages.com**. This year we had a great experience using CarePages to keep everyone up to date. CarePages is a website allows you to set up a free personal website (very user friendly!) and add the email addresses of the people who wish to receive regular updates. You go to the webpage from any computer (most hospitals have computers or wifi you can use) and type an update and/or picture and, when you post it, everyone on your list receives an email to with a link to the webpage. Friends and family can also post notes as well that you can review at your convenience (midnight when the hospital is settling down???). We set the CarePage up before a scheduled surgery in December and it worked wonderfully! I added notes throughout the day of surgery and the first few days after the surgery. We kept this up even after we got home so that people would not feel compelled to call and we did not have to worry about offending anyone by not taking a phone call or cutting a call short. We could also post when we were ready for visitors!!!

ACCESSIBLE VACATION!
This is not meant to be an advertisement for this resort; I was just very happy to see the advertisement and thought the some others might be as well!

VISIT FREEDOM SHORES FULLY ACCESSIBLE MEXICAN RESORT!
If you were ever disappointed on vacation because the hotel/resort staff just did not have time to bother with you, then you come to Freedom Shores! Our staff knows that the only reason they are here is to care for you & make you happy!

Freedom Shores is a newly constructed, universally designed resort complex on the Laguna de Terminos on the Gulf of Mexico. This beachfront luxurious island getaway was built by a quadriplegic who knows what the word accessibility really means! Bill & Thelma Bussear always dreamed of opening a place for wheelchair veterans in beautiful Mexico. In December of 2005, their dream came true! They renovated 2 1/2 acres of beachfront property, and created a wheelchair accessible resort in Isla Aguada, Campeche, Mexico with 300 feet of gorgeous beach on the Laguna de Terminos.

Freedom Shores is located 25 miles from the Ciudad Del Carmen, Campeche airport & is only a two-hour flight from Houston. Handicapped transportation is available to and from the airport for $50. The resort has a gorgeous, state-of-the- art restaurant featuring Jesus Damas, an amazing chef who offers a wide variety of American, Mexican, Italian, Chinese and other epicurian delights.

RESERVATIONS OR INQUIRIES: Contact William & Thelma Bussear
FROM THE USA - Tel: 951-801-2716 - Cell: 951-218-5364 - Fax: 951-742-8326
Email: **Bill@Freedom- Shores.com** Website: **www.isla-aguada.com**

Youth and Adults Group Update

A Preview to Upcoming YAG Activities

by Jen Kuhar

A big thank you to the nearly 20 folks who braved the snow on Saturday, March 1st to join us for lunch at Uno's Chicago Grill in Braintree. A great time was had by all. By now, most of us are thinking Spring and the warm weather will be here before we know it. There will be many opportunities to connect with others in 2008, and we will be making an extra effort to reach the various regions of Massachusetts. In May we will be in Sturbridge and in September we venture to the North Shore. Hopefully you can join us for a baseball game at LeLacheur Park, Home of the Lowell Spinners where they will take on the Hudson Valley Renegades. Mark your calendars NOW, watch your mailboxes and check our website often (**www.sbaMass.org**) for the latest in YAG news. We look forward to seeing you all throughout the year!

4/12/08	1:00PM Lunch at Kelly's Roast Beef (at Jordan's Furniture) Natick, MA
5/31/08	1:00PM Lunch at Picadilly Pub Sturbridge, MA
6/22/08 – 6/25/08	SBA Conference Tucson, AZ
7/19/08	Annual sbaMass Picnic Danehy Park, Cambridge, MA
8/10/08	Lowell Spinners vs. Hudson Valley Renegades (Baseball) T. LeLacheur Park, Lowell, MA (Limited seats available – 2 ticket limit per person, first come, first serve). Game starts at 1:35 PM and doors open at 12:00 noon. Deadline to reserve seats is July 28, 2008. E-mail **jkuhar@sbaMass.org** for more information or call 888-479-1900.
9/13/08	1:00 PM Lunch at 99 Restaurant Saugus, MA
10/25/08	Annual Lunch & Learn Morse Institute Library, Natick, MA Details TBD
12/7/08	Holiday Party

Note: Schedule subject to change.

Mark Your Calendars for the

Sixth Annual
sbaMass Summer Picnic

Saturday, July 19, 2008

12:30 pm - 4:30 pm

at Danehy Park

Cambridge, MA

Parking Lot and Picnic Area
near the office & restrooms

Map, Directions and RSVP Info
in the next newsletter

- ***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.

Board Meeting Notes & Updates

By Ellen Dugan

Below is a summary of what the sbaMass Board has discussed over the last few months. Board Meetings are held on the first Tuesday of each month at 7:00 PM 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 placed on the agenda, please contact any of us.

- The Board of Director's welcomes two new members, Kathleen Pease and Cara Packard. The sbaMass is grateful to their participation, energy and enthusiasm.
- The sbaMass continues our folic acid outreach efforts. In January we participated in Bridal Expos in Worcester and Boston reaching a combined 500 individuals. We will be attending two additional fairs in September. On September 21st sbaMass will be at the Sturbridge Host Hotel and on September 28th at the Sheraton Braintree
- Four dates are being scheduled for the Red Sox Community Home Stand. The Red Sox organization provides the opportunity for area non-profits to distribute information about their organization to fans. Check the sbaMass website for upcoming dates and stop by the booth if you are at the game.
- We will have an exhibit table at the MAssachusetts Early Intervention Consortium Conference, Marlboro, Ma on May 7th and 8th. In addition sbaMass will be presenting a breakout session entitled "Social and Emotional Development in Children with Physical Limitations".

Self-sufficient and going strong at 77, with Spina Bifida

by Tina Calabro

Two years ago, Bob Vosburg rolled into the wheelchair lab at Pitt's School of Health and Rehabilitation Sciences to see about a new seat cushion. While he was there, he gained an important piece of information that had eluded him for most of his 76 years.

A doctor in the clinic told him the name of the condition that had caused his lifelong disability -- Spina Bifida -- and that he might be one of the oldest people in the region with the condition.

"For the first time, I knew what I had," said Mr. Vosburg of New Castle.

Of course, he always wondered what exactly had caused the weakness in his legs. When he was born in 1930, doctors told his parents that his difficult breech birth injured the nerves in his spine.

"Those were the dark ages of medicine," he said.

Despite not knowing the name of his condition, he learned how to manage it during an era when it was far more difficult to do so than it is today. Now 77, Mr. Vosburg is a rarity: He can describe what it was like to be a child with a disability in those days and what it's like to age with a disability today.

Babies born with serious problems in the 1930s often were not expected to live, let alone reach old age. Doctors told Marion and Robert Vosburg of Scranton that their newborn son might live about five days. If he survived, they said, he would need a wheelchair his whole life.

Fortunately, leg braces, crutches or a cane have provided sufficient support for most of Mr. Vosburg's life. He didn't opt for a wheelchair until he reached his 50s and, by his description, "ran out of gas."

"My parents would not accept what the doctors told them as 'the end,' " he said. They were just "ordinary people," he said, but they sought out the best resources they could find. Their seeking led them to Pittsburgh, to what was then called the Industrial Home for Crippled Children (now The Children's Institute). They enrolled their son as a residential student when he was just 4 years old.

The "Home," as he still calls it, was founded in 1902 to care for and educate children with physical disabilities. By the time Mr. Vosburg arrived from Scranton in 1934, the Squirrel Hill facility had served hundreds of children and was about to open a new addition with a therapeutic pool.

His parents regarded the opportunity as a blessing, but it was also a sacrifice for them. As an office worker for a coal company and housewife, they certainly could not have afforded to pay tuition, said Mr. Vosburg, who assumes that his tuition was paid for by charity. In order to bring the family closer together, his father took a job with a coal company in Bobtown, Greene County, near the West Virginia border -- 80 miles away from Pittsburgh rather than 300.

Mr. Vosburg lived at the Home until he was 9. Memories from that period abound. The superintendent, Miss Frances E. Shirley, still looms large, as do the housemothers assigned to the separate boys' and girls' units. The frustration of having to eat everything put on one's plate. Piano lessons. Annual trips to Kennywood, which provided photo ops for the Pittsburgh newspapers.

"I knew every nook and cranny of the building," he recalled. Yet, when he attended a reunion in the early 1970s following a major renovation of the facility, very little was familiar. "I toured the whole building and did not see one thing I recognized." He searched in vain for the long flight of stairs that occupied an important place in his memory. "Where were they?"

He was tickled when a woman he didn't remember eagerly approached him at the reunion, "You're Bobby Vosburg," she exclaimed. "Hey, you were such a little guy."

The missing staircase could well be a metaphor for the steps "Bobby" made at the home. Perhaps ironically, the biggest changes in him did not involve his disability, but his attitude toward it.

"I walked into the home with two braces and a cane, and I left five years later with two braces and a cane," he emphasized. His disability had not changed, but he was a different child when he left the home, and not just because he was older.

"A seed was planted there," he said. "Very subtly, the people there made you self-sufficient. That's the biggest thing they did. In your own mind, you felt that you were not different from anyone else. They sent you back into the real world. I went back and didn't miss a beat."

He remembers blending in with his classmates in regular school when the family returned to Scranton. "I became a leader of kids I hung around with. I was treated no differently [than other kids] and wouldn't have had it any other way."

He graduated from high school and then Penn State, where he often trekked with his cane from one end of the campus to the other. Not long after college, he joined the New Castle News as sports editor and later became managing editor. He retired from a 40-year career with the paper in 1994. He met his wife, Phyllis, in New Castle. They have an adult daughter.

An auspicious meeting

The doctor Mr. Vosburg met at the wheelchair clinic two years ago was Brad Dicianno, a physical medicine specialist (also known as a physiatrist). The meeting was auspicious for both men. Mr. Vosburg learned that he could obtain services from UPMC's Adult Spina Bifida Clinic, which Dr. Dicianno heads. Dr. Dicianno gained a new patient who could teach him how people with Spina Bifida age.

Spina Bifida, Latin for "split spine," is a birth defect in which the embryonic neural tube is not fully closed, resulting in an incompletely formed spinal cord. Individuals with the condition experience some degree of dysfunction in the spinal cord and the nerves associated with it. The most common locations of these problems are the lumbar and sacral areas of the spinal cord. In some individuals, spinal cord abnormalities are visible through a skin opening on the back.

Worldwide, Spina Bifida is one of the most common birth defects, affecting one to two live births per 1,000. In the United States, the rate is lower -- 7 out of 10,000 live births. In recent years, studies have shown that taking folic acid supplements prior to conception decreases the incidence of spina bifida by 75 percent.

UPMC's Adult Spina Bifida Clinic, which also treats adolescents, was established in 2003. It's one of five specialty clinics of this type in the nation and draws patients from Pennsylvania, Ohio and West Virginia.

The very existence of a Spina Bifida clinic for adults is a new development. Not so long ago, Spina Bifida was considered a pediatric illness, and patients would simply continue to see their pediatric physicians into adulthood. The average life span for an individual with the condition was 30 to 40 years, with renal failure as the most typical cause of death.

Because of improved medical care, especially urologic management, people with Spina Bifida are living long lives and changing the way medical professionals think about the condition, said Dr. Dicianno. Older people with spina bifida are now experiencing many of the same problems as the rest of the aging population -- heart disease, obesity, certain cancers. Bob Vosburg, in fact, has been treated for prostate cancer.

Dr. Dicianno said that Mr. Vosburg, his oldest patient, has taught him about the complications that occur with aging. “He’s given me an appreciation of my own specialty, how we can coordinate care and make sure that everyone communicates.”

Looking back

When Bob Vosburg looks back on his childhood, he sees two key influences -- the home in Squirrel Hill where he was taught to believe in himself, and his parents, who went to great lengths to make sure he received the best possible treatment.

“I have no idea how my life would have turned out otherwise,” he said. “Maybe just the same, but I have to believe that it had an effect.

“Back then, many kids like me were stuck in a closet. I had parents who didn’t want to stick me in a closet.”

What’s better now, he says, is the medical advances and technology that allow doctors to look inside and see what’s in there and how to treat it. “But sometimes they can’t do a whole lot more, even though they can name it.”

The Adult Spina Bifida Clinic is at UPMC South Side Hospital Heart Station. For information, call 877-647-3438.

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Attitude Solution

by Rob Ingraham

Attitude is rated most important in determining health-related quality of life for adolescents with Spina Bifida.

While a positive attitude has always been considered an important factor in successfully adapting to a disability, researchers have begun to prove these assumptions in scientific studies.

Researchers in Wisconsin and Indiana recently examined health-related quality of life (HRQOL) issues for young people and adolescents with Spina Bifida and concluded that adolescent beliefs, rather than any characteristic of the condition itself, are most associated with HRQOL outcomes.

HRQOL was defined as a person’s perception of their well-being—their emotional, physical, or social status that might be affected by their condition.

What is Spina Bifida?

An estimated 70,000 people in the United States are currently living with Spina Bifida (SB) the most common permanently disabling birth defect. SB is a neural tube defect (a disorder involving incomplete development of the brain, spinal cord, and/or their protective coverings) caused by the failure of the fetus’s spine to close properly during the first month of pregnancy. Infants born with SB sometimes have an open lesion on their spine where significant damage to the nerves and spinal cord has occurred. Although the spinal opening can be surgically repaired shortly after birth, the nerve damage is permanent, resulting in varying degrees of paralysis of the lower limbs.

Up to 90% of children with the worst form of SB have hydrocephalus (fluid on the brain) and must have surgery to insert a "shunt" that helps drain the fluid—the shunt stays in place for the lifetime of the person. Other conditions include full or partial paralysis, bladder and bowel control difficulties, learning disabilities, depression, latex allergy and social and sexual issues.

Adolescents and young adults are especially at risk for multiple "negative adaptations" to SB because of the multiple organ systems affected by SB, which has resulted in significant personal and societal costs.

Negotiating Adolescence

In the current study, researchers defined adaptation as "success with the major developmental tasks expected for a person of a given age and gender in the context of his or her culture, society, and time. Adolescents who achieve high levels of adaptation are functioning well at home and school and are generally satisfied with life, school, and social activities." For adolescents, this adaptation includes becoming skilled in managing physical health, developing positive mental health, such as positive self-esteem without behavioral problems or depression, while "developing age-appropriate social friendships and romantic competencies and achieving academic success."

In a review of the existing scientific literature on HRQOL and chronic illness in young people, the researchers cited earlier studies that found that children and adolescents with a variety of chronic health conditions generally had lower HRQOL than their peers, but there was "substantial" individual variation. In addition, when examining the impact of their condition on HRQOL, many researchers found that adolescents and young adults report that the type of condition or its severity is not the most significant factor in explaining HRQOL.

In a pilot study released in 2002, the researchers found "strong and consistent relationships between HRQOL and adolescent beliefs such as attitude, efficacy, hope, and coping, as well as significant family resourcefulness measures such as family satisfaction, family overprotection and family activity."

Living Well with SB

In the current study, 72% of the adolescents and young adults in the study resided in primarily two- parent families who were generally well educated and had a range of family incomes. Participants were between 12 and 25 years old, were 62% female, and primarily Caucasian. Ninety-five percent of the participants had a shunt.

The researchers found that the variable with the strongest relationship to HRQOL was the adolescent's attitude toward SB. "While we do not expect adolescents to have a strong positive attitude toward having SB, developing the perception that one can live a full life with relatively few restrictions in spite of the challenges of SB, does seem to be a strong protective factor for youth in this sample. Perceiving SB as having a major negative impact on one's life is related to more negative HRQOL outcomes."

"[T]he data in this study support our previous findings of differential patterns of factors associated with HRQOL and functional status outcomes. While SB neurological severity contributes substantially to functional status, its contribution to HRQOL appears to be much smaller."

The researchers noted that a main challenge for adolescents and young adults with SB is developing ongoing positive coping strategies and stressed that mental health services should be a central component of treatment.

"Clearly, as we transition adolescents and young adults to adult health care we need to continually query the adolescents and families not only about the adolescent's functional status, but the adolescent's and family's satisfaction with a wide range of issues regarding care."

Discussing the study's implications for health care providers, researchers stressed that nurses, specifically, and other SCI team members need to remember that different factors are potentially related to two major targeted outcomes: functional status and HRQOL.

"If they are targeting HRQOL, interventions should address beliefs such as attitude or satisfaction with clinical status or family function. If the health care provider is targeting improvements in functional status, however, addressing interventions that impact decision-making participation and household responsibility may be optimal."

The study, "Individual and Family Factors Associated with Health-Related Quality of Life in Adolescents and Young Adults with Spina Bifida," appears in SCI Nursing, the online journal of the American Association of Spinal Cord Injury Nurses and can be viewed by visiting AASCIN's Web site at **http://www.aascin.org/**.

Authors of the study are Kathleen J. Sawin, DNS, CPNP, FAAN, a professor at the College of Nursing, University of Wisconsin-Milwaukee Children's Hospital; Constance F. Buran, DNS, RN, Riley Hospital for Children, Indianapolis, Indiana; Timothy J. Brei, MD, Riley Hospital for Children; and Susan E. Cashin, PhD, College of Health Sciences, University of Wisconsin-Milwaukee.

For more information on spin bifida and current research trends, readers are urged to visit the Spina Bifida Association of America at **http://www.sbaa.org**.

Reprinted with permission from the United Spinal Association

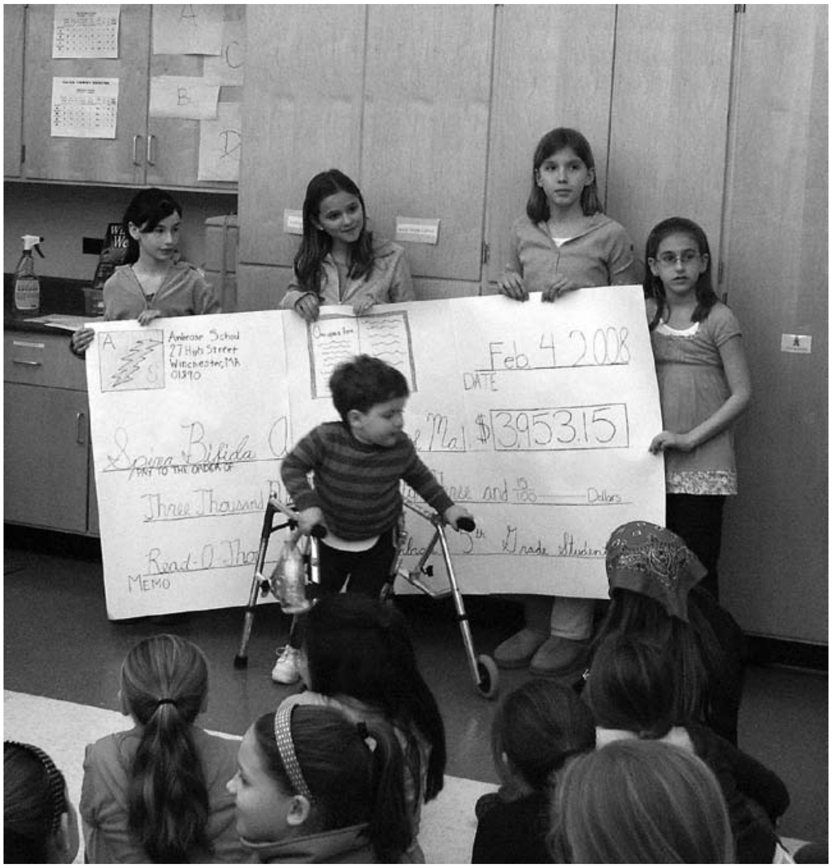
Read-a-thon at the Ambrose School in Winchester, MA

by Ellen Dugan

The fifth grade students of Ms. Cataldo, Ms. Ring and Ms. Dwyer, completed a Read-A-Thon fundraiser during their Holiday Break. Before their Holiday Break, students volunteered to speak in front of their classmates to suggest worthy organizations for our fundraiser. Students candidly gave accounts of their grandparents who had Alzheimer disease, family members who had died of cancer, and also friends who had diabetes. Yet the favored organization, by far, was the Spina Bifida Association of Massachusetts.

The students read as many pages as they could during vacation and contacted sponsors who pledged a per page amount. The students combined efforts raised over $3900 for sbaMass.

The sbaMass would like to thank the fifth grade students at the Ambrose School for selecting sbaMass as the recipient of his year's efforts. The sbaMass also greatly appreciates the efforts of Ms. Cataldo, Ms. Ring and Ms. Dwyer in organizing this project. The funds raised this year support sbaMass efforts to provide financial benefits to sbaMass constituents. Thank you to all!



2008 SPINA BIFIDA ASSOCIATION of Massachusetts

CHARITABLE EVENT

FOURTH ANNUAL GOLF TOURNAMENT

SKY MEADOW COUNTRY CLUB

Nashua, New Hampshire
www.skymeadow.com

Monday, May 5, 2008 Shotgun Start 1:30 pm

GOLFERS: $25 IN RAFFLE TICKETS IF YOU SIGN UP BY MARCH 1st, 2008!

SPONSORS NEEDED: Major Sponsors to Friends of the Spina Bifida Association of Massachusetts

AUCTION ITEMS NEEDED: Sports tickets, vacation home stay, etc.

CELEBRITIES: Include a famous sports, business or entertainment figure in your foursome and you both play for free!

VOLUNTEERS: Positions are open for assistance prior to and during the day of the event.

CONTACT US TODAY!

CONTACT INFORMATION

Spina Bifida Association of Massachusetts

Ellen Dugan, Operations Associate
Website: **www.sbaMass.org** (all forms and details)
Toll Free: (888) 479-1900
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CONTACT US TODAY!

SBA 35th National Conference
Tucson, Arizona
June 22-25, 2008

at the

JW Marriott Starpass Resort

www.jwmarriottstarrpass.com

CONFERENCE REMINDER!!!!

Conference scholarship applications due April 4, 2008

CHECK OUT THE FOLLOWING WEBSITES AND YOU WILL WANT TO ATTEND CONFERENCE WITH OR WITHOUT A SCHOLARSHIP!!!!!

www.visittuscon.org – Convention and Visitors Bureau
www.tusconas.gov/visitor - City of Tucson
www.go-arizona.com/tuscon - sponsored website
www.cs.arizona.edu/camera/ - University of Arizona webcam shot
www.tripadvisor.com – personal reviews on restaurants, sites and more

Please check out the SBA website for HELPFUL INFORMATION: Go to **www.sbaa.org**, under Programs/Services, click SBA's national conference, scroll half way down to page to 35th National Conference Website. The website does a great job of covering the conference basics from getting there to things to do around Tucson.

Register online today at **http://conference.spinabifidaassociation.org** or call 800-621-3141 to have a packet sent to you.

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!

The sbaMass REALLY Wants You to go to the SBA National Conference this June in Tucson, Arizona!

sbaMass will even help pay for it!

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

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

You need only provide an application with:

- Letter with 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)
- Your willingness to write an article, take pictures or someshow share your experience
- Signed application / contract (see below)

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) 926-7700 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

Important Dates

SBA 2008 Annual Conference
June 22 - 25, 2008
Tucson, AZ

Application Submission Deadline: April 4, 2008

Notification Deadline to Scholarship Awardees:
May 1, 2008

Formal Announcement at sbaMass Golf Tournament:
May 5, 2008

The sbaMass ANNUAL BENEFITS PROGRAM
$500 for 2008

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) 926-7700 or leave the information and request in a phone message at (888) 479-1900.

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 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 16, 2008*.**
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) 926-7700 and request the Jean Driscoll Scholarship Package. Be sure to include your name, address, and phone number and (if available) e-mail address.

Contacts

sbaMass Tel. (toll-free) (888) 479-1900
sbaMass Fax (978) 926-7700

SBA Tel. (toll-free) **(800) 621-3141**

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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.

We're Looking for Office Space!

The SBA of Massachusetts is continuing to seek free or low cost office space. The ideal space would be located on or near Route 128, (accessible to The RIDE), and include space for 3 desks, meeting space to accommodate up to 20, wheelchair accessible, 24/7 access and accessible restrooms. Shared space with another non-profit or business will be considered.

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

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