

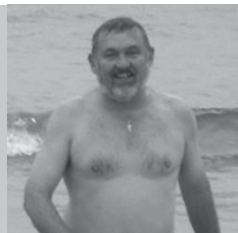
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Holiday
Party



4
Hannah
Farrell



4
Robert
Day



10
2009
Calendar



sbaMass

3 | 8

YEARS

1971-2009

Letter from the President

by Brendan Sullivan

Accomplishing Goals.

Last October, the Board of Directors of sbaMass met for our annual meeting. The purpose of this meeting is to provide a review of goals accomplished in the past year, assess needs, and develop future goals to meet those needs. At that meeting, the Board identified two important goals for the continued progression of our organization. First, the Board needed to expand and add individuals that possessed both a desire to help our community and a professional skill or knowledge that could be helpful to the organization. Second, to be a fully-functioning organization we needed proper office space so that we could better serve our community.

Well, in just the first month of 2009 I am happy to report to you that we have accomplished both of those strategic goals. First, we have added three dedicated, knowledgeable, and service-oriented individuals to our Board of Directors. Joining the Board are Dr. Stuart Bauer, Mary Jo Dunleavy, and Barbara Lee. Dr. Bauer is a noted urologist at Children's Hospital and serves many children with Spina Bifida. Dr. Bauer is also a key organizer of the First World Congress on Spina Bifida Research and Care – a conference occurring this March that will bring specialists from around the world together to discuss the future of care for individuals with Spina Bifida.

Our second newest board member, Mary Jo Dunleavy, I am certain is familiar to many. Mary Jo is a nurse at Children's Hospital and heads their Spina Bifida clinic. She also serves on the Professional Advisory Council of SBAA. And our third newest member, Barbara Lee, has been working with non-profits for a majority of her career and focuses on special events and planning.

I speak on behalf of the entire Board of Directors as well as our community as I say thank you to these individuals for committing to improving the lives of individuals with Spina Bifida in our community.

Finally, for the first time in sbaMass' history – we have office space! For more details on location please read the article that appears later in this newsletter. We are very excited about this step in our progress!

In closing, I hope the New Year finds each and every member of our community in good health, good spirits, and working towards something that is personally rewarding.

With wishes for good health,

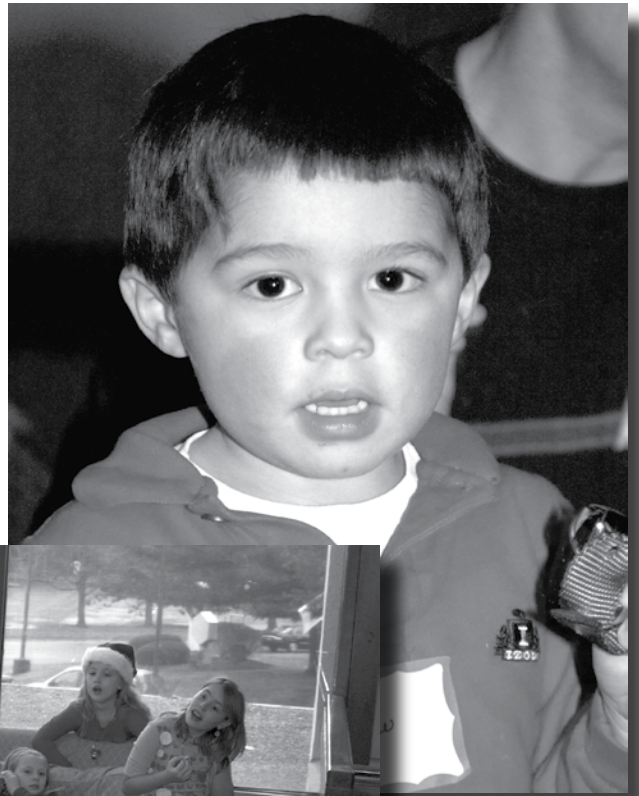
Brendan Sullivan

President

**Thank You to the following
companies for their
donations to the
sbaMass Holiday Party**

*American Doll Company
Building 19 Foundation
Basketball Hall of Fame
Brigham's Ice Cream
Children's Museum, Providence
Ecotarium, Worcester
Franklin Park Zoo / Stone Zoo
Davide Restaurant, Boston*





Robert Day: Let's Jump in for Spina Bifida!

On October 13th, 2008 at 1 PM, Bob Day and a group of family and friends took their last swim of the season at Old Orchard Beach, Maine. Bob has been taking this last swim on Columbus Day for 44 years and created this event to remember his son Bobby Jr. along with his father William E. Day, Sr. Bobby was born with Spina Bifida and through his life endured many surgeries. In 2004 at the age of 26 Bobby died ending his battle. His Grandfather died a mere 15 months later at the age of 96. Although they had two quite different lives they both enjoyed the Ocean. Bob Day decided that this being his 45th year it would be fitting to establish this event to honor his Son and Dad by raising money for Spina Bifida. Bob, his family and friends received pledges for their "jump in" and raised over \$1200 for sbaMass. Bob would love to have you join him next year!



Hannah Farrell and JennyBoston

Hannah Farrell has a younger brother Sean, pictured with Hannah (right), who has Spina Bifida. She has always supported her older brother, Ryan, when he ran in the Falmouth Road Race as part of Team sbaMass. This year Hannah wanted to do something on her own to assist sbaMass in ongoing fundraising efforts. During the fall she held a pocketbook and jewelry fundraiser working with a company called JennyBoston. The total raised by Hannah and donated to sbaMass from the JennyBoston (www.jennyboston.com) party and other donations exceeded \$1,800. JennyBoston donated 25% of Hannah's total sales to sbaMass.



Bits & Pieces

by Hyacinth Bellerose



COLD????
TIRED OF
WINTER
ALREADY?



SUMMER CAMP! Now is the perfect time to start planning!!!! I am always on the lookout for local resources and Framingham's Special Education PAC has the most complete and useful list I have seen yet. There are even lists of water parks and playgrounds in the Metro west area (with details on accessibility). Check out their website at www.f-sepac.org and click the button for summer camps. The references are to and contacts for:

- camps that participate in the annual expo
- recreational organizations
- how to choose the right camp
- transitional programs
- travel and vacation opportunities

This year's **Summer Camp Expo is February 8, 2009** from 12-4 at the Framingham High School (115 A Street). Speak with the representatives to find out what is out there for you and your family!

FUN IDEA: Put together a listing of water parks and playgrounds in your area to share!

WINTER BIRTHDAY? Throw a beach party!!! Tell guests that shorts are required as you are turning up the heat!

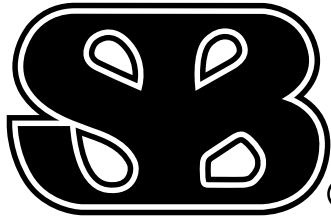
- Hawaiian leis on arrival
- The Beach Boys and surfin' music
- Hamburgers and hot dogs, icy drinks with umbrellas, build-a-sundae, fruit and salads
- Beach ball volleyball (no standing allowed), ball pit in a kiddie pool, conga line
- Relax picnic style or on beach chairs, hang colorful beach towels
- Pirate theme with a scavenger hunt

For a special treat, find an indoor pool in the area (a hotel, the Y) and get a day pass!

PREPARE FOR SUMMER If you want to make sure that you are ready to head outdoors when the weather changes, get your chores behind you!

- Winter cleaning instead of spring cleaning – curtains, cobwebs and under the beds!
- Organize your finances, prepare your tax return early, set up the perfect filing system for easy bill pay the rest of the year, get doctor's appointments out of the way
- Pull your summer pictures and mementos and finally start an annual photo album that you are allowed to ignore when the weather is nice and catch up on under a blanket on a cold afternoon.
- Clear out kitchen and bathroom cabinets, dig to the back of the closet
- Get ahead at work to avoid late nights come summer

**But if you are the type to ski, prefer hot chocolate to lemonade, enjoy a book and blanket on a cold day
JUST ENJOY!**



**SPINA BIFIDA ASSOCIATION
OF MASSACHUSETTS**

(Serving MA, NH, RI, ME and VT)

CHARITABLE EVENT

FIFTH ANNUAL GOLF TOURNAMENT

Sky Meadow Country Club, Nashua, NH

www.skymeadow.com

Monday, July 20, 2009

Shotgun Start 1:30 pm

Save the Date!

BUT Now....We need your help for:

**GOLFERS
AUCTION ITEMS
GOLFER GIFTS
VOLUNTEERS**

**ENTERTAINMENT
RAFFLE ITEMS
GOODY BAG ITEMS
DINNER GUESTS**

Joyce McKenna Hillis

Tournament Chair

(603) 224-7761

hillisj@cwbpma.com

Ellen Heffernen-Dugan

sbaMass Operation Associate

(888) 479-1900

edugan@sbamass.org

REGISTER ONLINE AND WATCH FOR UPDATES AT www.sbamass.org

sbaMass has a New Home!

On January 1st, sbaMass moved into office space at 321 Fortune Blvd in Milford, MA. The office is close to the Mass Pike and just off Rte 495. This move to space outside of volunteer and staff homes has been much anticipated. Although the office is not large, approximately 300 sq ft, it is hoped that sbaMass will be able to have some of our upcoming events and meetings there. The office is on the first floor of a medical/professional building, fully ADA accessible with ample parking. At present the phone and fax numbers will remain the same. Regular office hours will be established in the upcoming weeks, as soon as the internet and phone systems are ready to go.



Thank You!

As in years past the **T-Stop Variety Store, Lynn, MA** has continued their generosity to sbaMass. In 2008 **Anthony and Susan Leo** and their generous customers have raised \$500 for sbaMass, from the canister in their store. Thank you to the Leo's for their ongoing dedication to sbaMass and to their customers for their continued commitment to the individuals served by sbaMass.

sbaMass would like to thank **Marianne DiBlasi** for her hard work on the **Adopt a Ghost Program**. Marianne raised over \$400, setting up a table after church services. Thank you to Marianne, her friends and neighbors for their generosity. The Adopt a Ghost program is an awareness and fundraising activity sponsored by SBA Chapters across the country. The Adopt a Ghost Program is planned for October of each year, Spina Bifida Awareness Month. If you would like to participate in 2009 and have ideas for a possible venue, contact Ellen Heffernan-Dugan at edugan@sbaMass.org.

Thank you to **Normandy Realty and Seth Campbell** for their providing meeting space for sbaMass Board Meetings and Program Committee Meetings.

The sbaMass would like to express our appreciation to **Hannah, the Farrell Family, JennyBoston, Bob Day, and the Day Family and friends** for their efforts on behalf of sbaMass.

Looking for a Good Home!



Four cases on youth-size diapers are available (like MassHealth supplies). The diapers are located in South Boston. Donor is willing to deliver them within 15 miles or so for a little gas money or they can be picked up almost anytime. Please contact at pcaworker@aol.com.

A Quickie wheelchair in pretty good shape is available. Please contact Joanne Mahoney at (781) 894-2749 if you have an interest.



Do you have items to donate? Let us know and we'll include them in the sbaMass newsletter and website.

Contact Ellen Heffernan-Dugan at edugan@sbaMass.org

New Surgery To Improve Bladder Function Under Development

By Ginny Briggs

Some of the most common and serious complications faced by people with Spina Bifida are incontinence and urinary tract infections (UTI). Catheterization and antibiotics have been very effective in controlling these problems, but UTI's, continence and kidney health are still constant concerns for most. In the last few years, a new treatment has been emerging that may provide a vast improvement to the current methods. In China, a new surgical technique has been explored in both people with spinal cord injuries and in people with Spina Bifida, and has shown some very promising results.

The procedure is called "reinnervation of the neurogenic bladder", which means restoring nerve function to a bladder that is not working well. It involves re-routing the nerve that controls bladder function to a different place on the spine. By using a nerve higher in the spine to control their bladder (usually lumbar 5 or above), the person can cause their bladder to empty by simply scratching their leg in a certain place. This procedure has been performed on both people with spinal cord injuries and on people with Spina Bifida. In 2003, the results of a clinical study about this was published by a team of researchers from the Tonghi Medical College in China, New York University School of Medicine and University of Pittsburgh School of Medicine. They studied 15 males with spinal cord injuries and found that 13 had improvement in bladder control, a decrease in UTI's and marked improvement in urodynamic study results within 12-18 months after surgery. In 2005, another study was published that showed similar results in a group of 20 children with Spina Bifida (17 showed marked improvement). It was later reported in 2006 at an international conference in China that the procedure had been performed on 110 children with Spina Bifida with an 87% success rate after one year.

There has been great interest in learning more about this surgery in the U.S. and at the first "World Congress on Spina Bifida Research" scheduled in 2009 in Orlando, Florida, the leading urologist and researcher for this surgery will be presenting and discussing this in detail. In the future, there may be a clinical trial for this surgery to look forward to in the U.S..

References:

- 1) Xiao CG, Du MX, et. al An artificial somatic-central nervous system-autonomic reflex pathway for controllable micturition after spinal cord injury: preliminary results in 15 patients. J Urol. 2003 Oct;170(4 Pt 1):1237-41.
- 2) Xiao CG, Du MX, et. al An artificial somatic-autonomic reflex pathway procedure for bladder control in children with Spina Bifida. J Urol. 2005 Jun;173(6):2112-6.
- 3) Xiao CG. Reinnervation for neurogenic bladder: historic review and introduction of a somatic-autonomic reflex pathway procedure for patients with spinal cord injury or Spina Bifida. Eur Urol. 2006 Jan;49(1):22-8; discussion 28-9.

**sbaMass
constituents should review
all benefits requirements, before submitting
applications, as some requirements have been changed
for 2009. Please contact Ellen Heffernan-Dugan at
edugan@sbaMass.org or (888) 479-1900 with
any questions.**



Is This Your Year to Dream Big?

The sbaMass Board of Directors has revised the Jean Driscoll Scholarship for 2009, renaming it the Jean Driscoll Award. The award may be used for future educational pursuits, camps or training courses taken to improve the applicant's skills in an area of interest to the applicant. The award will be granted to a person, age 14 through adulthood, who, like Jean Driscoll, is achieving his or her goals despite any limitations imposed by Spina Bifida and who best demonstrates the character and determination of the award's namesake.

Jean Driscoll, who was born with Spina Bifida and has used a wheelchair since her early teenage years, is an accomplished athlete and speaker known around the world. She has enjoyed a life many people can only dream about experiencing. Jean is an Olympic athlete who has won Silver medals in both the 1992 and 1996 Summer

Olympic Games. She is a world record holder in the 10,000 meter track event, 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, Illinois and a park pavilion named after her in Urbana, Illinois. For more information about Jean Driscoll to understand the nature of this award, please feel free to review the following: www.jeandriscoll.com.

Look for additional information about the award in the Spring sbaMass newsletter and on the sbaMass website, www.sbaMass.org.

Dough Rai\$ers



Uno is proud to support the local communities it serves with our hugely popular Dough Rai\$ers program. Here's the Scoop (or slice): Host a lunch, dinner or both at your local

Uno and earn up to 20% of sales generated from guests who eat at Uno to support your cause. Dine in or take out. On the date of your Dough Rai\$er, come in and enjoy our delicious meals, including Uno's Legendary Deep Dish Pizza, mouthwatering steaks, crisp salads, juicy burgers and other tempting entrees. How's the donation ticket process work? Prior to the event, you'll distribute donation tickets to supporters planning to visit Uno during your Dough Rai\$er. Guests then present their donation ticket when they arrive at Uno for the Dough Rai\$er. This ensures that a percentage of their bill is donated to your organization.

If there is an Uno in your neighborhood and you are interested in helping facilitate a local event, contact Ellen Heffernan-Dugan at (888) 479-1900 or edugan@sbaMass.org. This is a great opportunity to raise some funds for sbaMass as well as to meet with other members of the Spina Bifida community in your area. The sbaMass will do the background work, you will just need to be there to greet others and enjoy your meal!

2009 Calendar

(All dates subject to change)

January

Tuesday 1/6 - Board Meeting 7 PM
Sat/Sun 1/24-25 – Marlborough Bridal Show

February

Sunday 2/15 - Foxboro Bridal Show

March

Annual Appeal – March 2009
Saturday 3/21 – Parents of Young children Meeting (ages newborn-age 6)
Saturday 3/21 – YAG Lunch

April

Tuesday 4/7 – Board Meeting – 7PM
Saturday 4/25 – Tween Meeting (ages 7-12)

May

Saturday 5/2 – YAG Lunch
Saturday 5/16 – Teens Group (ages 13-17)

June

Saturday 6/13 – YAG Lunch
Sunday 6/28 – Friday 7/3 – SBA National Conference, Orlando, Florida

July

Tuesday 7/7 – Board Meeting - 7PM
Saturday 7/18 – Summer Picnic
Monday 7/20 - Golf Tournament

August

Sunday 8/9 - Falmouth Road Race
Saturday 8/29 – YAG Lunch

September

Saturday 9/12 – Teens Meeting

October

Saturday 10/3 – Tween Meeting (ages 7-12)
Tuesday 10/6 – Board Meeting 7PM
Saturday 10/24 – 5th Annual YAG Lunch and Learn

November

Saturday 11/14 – Parents of Young children (newborn-age 6)

December

Sunday 12/6 – Holiday Party

Dates to be determined:

*Red Sox Community Home Stand

*Lowell Spinners Family Day

Check the website (www.sbaMass.org) for updates and changes

Contacts

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sbaMass Fax (978) 926-7700

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

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Committee Chairpersons

Arnold Chiari Information

Kevin & Maureen Walsh

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Also try World Arnold Chiari Malformation Association at

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

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Ginny Briggs

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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.



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