sbaMass news

Fall 2009 The Newsletter of the Spina Bifida Association of Massachusetts

2 **Mary Jo Dunleavy Scholarship**

4 **Cadette Family Golf Tournament Update**

5 **National Conference Report**

9 **Team sbaMass Runs in FRR**

sbaMass

3 8

YEARS

1971-2009

Letter from the President

HELLO sbaMass COMMUNITY! As the summer has ended and the fall has brought about a new school year and cooler days I hope this newsletter finds you and your family well in mind and body.

Since I last wrote, the sbaMass community lost a dear friend when Children's Hospital RN and sbaMass Board member **Mary Jo Dunleavy** lost her battle with cancer. Those that worked with Mary Jo, both at Children's and sbaMass, as well as those patients touched by her care, concern and advocacy feel an incredible loss with her passing. She was a valiant advocate, talented professional, and most of all, a caring voice in a world that was uneasy and scary for patients and their parents. We will miss her deeply. She can't be replaced, but we will work tirelessly as a community to ensure her spirit for advancing the lives of those living with Spina Bifida continues.

In this letter, I would also like to take the occasion to inform the sbaMass community that my term as President, which expires in December, will be my last term on the Board of Directors. After eight years of service, I am stepping away so that I may increase focus on other pursuits in my life. I leave with unbridled enthusiasm for the direction and future success of sbaMass. I can't begin to estimate the total hours I have spent on sbaMass work in the past eight years, but I know that what sbaMass has given back to me in terms of people, events, and opportunities is far greater than the work I put in.

At the recent Annual Meeting, **Mrs. Cara Packard**, previous Vice President, was named Chair of the Board of Directors and will serve a one-year term. With simultaneously growing opportunities and needs for sbaMass and the community it serves, the organization could not be in better hands than those of Cara and the remaining Board members.

I'll conclude by saying thank you. Thank you for the wonderful opportunities you've provided me in my service to the organization over the past eight years. I entered as a fresh college graduate eager to help and I leave as a working professional that now has two Boston marathons completed and a wealth of knowledge, experiences, and memories. I hope that I have left something of equal value behind.

Best regards,
Brendan Sullivan

PASSING OF A FRIEND AND ADVOCATE

sbaMass MOURNS THE LOSS of a friend and advocate. On Friday September 4, 2009 Mary Jo Dunleavy, passed away after an illness of several months. During her career of more than 30 years at the Children's Hospital in Boston, she worked at the urology and general surgery departments and most recently served as nurse coordinator of the hospital's Spina Bifida clinic. The thoughts of the Spina Bifida community of Massachusetts are with the Dunleavy families during these next difficult times. Mary Jo was a dedicated nurse and friend of sbaMass. She will be greatly missed by all her knew her.

sbaMass has placed a condolence book at the Myelo Clinic at Children's Hospital. During your upcoming appointments, please sign and leave a message for Mary Jo's family. In addition if you would like to send a card to Mary Jo's family, please forward to sbaMass, 321 Fortune Blvd, Milford, MA 01757. The sbaMass will forward all expressions of sympathy on to her family.

Mary Jo Dunleavy Scholarship

IN HONOR OF MARY JO, sbaMass has developed the Annual Mary Jo Dunleavy Scholarship. This scholarship will be awarded annually for a family to attend the SBA Conference. Mary Jo was a strong believer in the benefits of families attending this conference, both for the learning as well as the networking. Lifelong friendships are made at this conference and Mary Jo was conscious of the importance of these connections.

Log onto www.sbaMass.org and click on the Mary Jo Dunleavy link. It will bring you to the Memorial Wall in Mary Jo's honor. Your donation to this wall will build the foundation of the scholarship fund, allowing it to continue for years to come.

Bits & Pieces: Getting Around

Hyacinth Bellerose

The new Rabbit is suitable for children between the age of 1 to 18 years. The functionality of the Rabbit stays the same. It still provides children with the opportunity to explore and enjoy new and exciting adventures. The standing position entices the child to actively participate in things around him or her. The mobility of the Rabbit is similar to that experienced by active wheelchair users. Visit www.snugseat.com.

Designed to assure good seating posture, the First Class Chair school chair is comfortable, attractive and adjustable. It is ideal for physically challenged children with mild to moderate involvement for use in the classroom, clinic or home. Its multiple adjustments and accessories meet the needs of each child as they grow and develop. Visit www.wenzelite.com/firstclass.html for more information.

For information regarding funding an Adaptive vehicle: log onto Special Needs Resource Project September Newsletter Funding Wheelchair Accessible Vans and Lift Conversions has been released. Please visit www.SNRProject.com/newsletter.html.

(W)hole Shop Level One

ON NOVEMBER 7 & 8 (and on April 10 & 11, 2010), Mlarianne DiBlasi is leading a weekend workshop, called (W)hole Shop - Level One, which teaches the Wisdom WAY™ - a unique and potent process of self-empowerment, developed by Alaya Chadwick. This (W)hole Shop is open to the general public with a special invitation extended Adults, Parents and Family members whose lives are touched by Spina Bifida. Learning and using the Wisdom WAY™ changed Marianne's life, and in particular, her relationship to living with Spina Bifida. She is especially excited to share the Wisdom WAY™ with individuals in the Spina Bifida community. At the (W)hole Shop people will learn a way to make more empowered choices, thus creating more authentic power, freedom and hope in their lives.

Programs and Events to Support the sbaMass Spina Bifida Community

ON SATURDAY AUGUST 15TH at Boston Children's Hospital, the sbaMass Program Committee sponsored a half day talk, "Managing Systems: Exploring the Unique Stresses of Living with Spina Bifida". Marianne DiBlasi's (W)hole Life Coach and Mentor, Alaya Chadwick, generously created and gifted this talk to the Spina Bifida community.

At the event, parents of children who were born with Spina Bifida and adults living with Spina Bifida came and shared their experiences with each other. Alaya led the group through an afternoon of learning how to make different types of Spina Bifida related decisions, providing tools for self-care and renewal, and guiding a group discussion. Some comments from people who came were "This was the most impactful event about Spina Bifida that I've ever attended" and "These decision-making tools are great. They can also be used in other areas of my life", and "Very worthwhile and eye opening. I appreciated the chance to talk about and share the emotional side of Spina Bifida – you don't get to do that very often."

Marianne is in discussions with Alaya and sbaMass to offer this talk again in the early Spring. Look for communications from the sbaMass Program Committee for information about this talk and other upcoming events.

In addition to sbaMass sponsored programs, as the Director of Awakening Life Coaching, Marianne is extending an invitation to individuals in the Spina Bifida community to participate in other events that she is offering.

On the first Wednesday evening of the month, Marianne is gifting a Monthly Conversation for those whose lives are touched by Spina Bifida. Her intention is to provide a place for people to come together and talk openly with others who live with Spina Bifida. It's a place to share challenges, learnings, celebrate accomplishments, and provide mutual support from a variety of viewpoints.

Information You Can Use

- SBA has a new publication for purchase entitled "Bowel Manangement and Spina Bifida" It is available thru SBA. Log onto www.sbaa.org and click on Marketplace.
- A great website for young girls/teens/women. The Center for Young Women's Health of Children's Hospital. They have a companion site for young men as well. Visit: www.youngwomenshealth.org.

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.

Thank You

The following companies have recently matched employees gifts to sbaMass

Bank of America / GE Foundation / Verizon

Special thanks to Childrens Orthopedic Surgery Foundation for their ongoing support of sbaMass and its constituents

If you are uncertain if your employer has a Matching Gift program, log onto ***www.sbaMass.org*** and link to Matching Gifts.

Cadette Family Golf Tournament a Great Success!

sbaMass IS VERY PROUD AND EXCITED to have a new family involved in our fundraising efforts - the Cadette Family. **George and Olivia Cadette** have two sons, **Matthew and Andrew**. Matthew was born with Spina Bifida and is a very active young adult. In June of this year, George's family, led by Olivia and supported by George's brothers Joe and John, decided they would organize a golf tournament to support sbaMass. I do not think that anyone of the golf committee expected the event to come together as well as it did given the short amount of time. But, in the tradition of our past four golf tournaments, the weather was perfect and everyone had a great time. In just three short months, the Cadettes pulled from family, friends and business associates to fill the golf course with 145 golfers and to raise approximately $50,000!!!!!!!!

George, Joe and **John** own Dunkin Donuts franchises in the Shrewsbury, Fitchburg and Brockton areas. They called upon their fellow franchise owners and the donations poured in from Dunkin Donuts owners throughout eastern and central Massachusetts.

Because of the success this year and the needs associated with the Spina Bifida Association of Massachusetts, the Cadette/Cadete families have agreed to made the tournament an annual event. Please mark your calendars for September 20, 2010 in you wish to participate in sponsoring, volunteering and/or playing in next year's tournament!

Matthew Cadette (front), Eric Eskander, Carlos Rezendes and Jason Cadete (back)

Matthew Cadette with his Uncle Joe

Olivia and George Cadette

Andrew Cadette, Joe Bolarinho, Brian Andrade and Kevin Andrade (L to R)

Thank You Sponsors!

- George Cadette and Family
- Joe Cadette and Family
- John Cadette and Family
- John Batista and Lisa Batista of C & L Donuts Inc.
- Rollstone Bank & Trust
- Montuori Oil Corp
- Wayne J. Golab of Fred C. Church Inc.
- Clemente Family Charitable Trust
- Lisa & Sousa, Ltd. Attorneys at Law
- Salema Cart Systems
- L.A. Window Cleaning
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- Lamiflex/Powerflex
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- Flynn's Truck Plaza
- Torrey St Dunkin Donut
- J&S Caravela, Inc.
- Joyal Capital Mngmt
- In Memory of Tony DaSilva
- A&A Donuts Inc.
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- MacDonald Restaurant Repair Service Inc.
- Services Plus Mechanical
- Central MA Orthodontic Associates PC
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- Francis F. Riley and Patricia M. Riley
- In Memory of Urbano Cadete
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- Howland Disposal
- National DCP LLC
- Attraviana Full Service Salon
- Matthew and Andrew Cadette
- Drew Mortgage and Associates
- Prazeres Charity Fund Account
- HomeLand Builders
- Stephanie Teixiera
- Anna Resendes
- Ma's Donuts & More
- Medeiros & Jacinto LLC
- Cafua Management
- Tony and Victoria Travasos

2009 Spina Bifida National Conference Report

Sara Haywood

ATTENDING THE 2009 SPINA BIFIDA ASSOCIATION CONFERENCE was certainly an educational experience I will never forget. Not only did I get to attend fascinating sessions on orthopedics, bladder and bowel control, female health and guidelines for attending college with a disability, but I was able to educate others as well. The beautiful Swan and Dolphin Resort in Orlando, Florida provided a comfortable atmosphere for myself and others, with the birth defect that I learned affects over 170,000 Americans, to socialize and learn about each other. My experience at conference has certainly inspired me to not only get involved with as many organizations as I can, but helped me learn that I am sharing the same struggles as thousands of others.

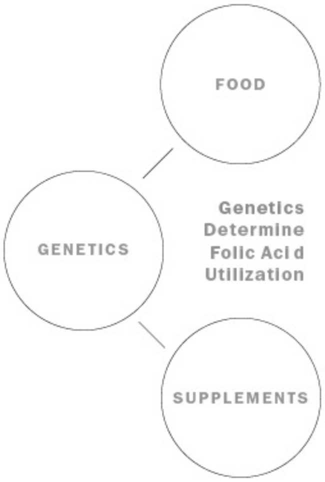
Upon entering the Swan and Dolphin Resort I was excited to escape the almost unbearable humidity of Florida and even more excited to see a sea of wheelchairs and crutches, smiling faces and even a couple of familiar ones. No one stood out or was ashamed of their disability and this feeling of community was very empowering yet comforting. I checked in, got my packet and immediately began searching through the sessions trying to decide which ones were most important to me. How could I choose? There were at least twenty fact-filled sessions being held but I had to narrow down my choices. My first stop was the adult day, where I met some very important people in the world of disabilities and learned about my options for college and how I need to advocate for myself. It was nerve-wracking to find myself alone in a huge resort searching for the different meeting rooms but I immediately made friends with from people from many different states.

I attended a couple sessions that dealt with bowel and bladder issues, something I have always struggled with myself. There were mostly aimed at parents who have young children with Spina Bifida, but of course I found the advances and new procedures interesting. The most educational part of the conference was the orthopedic question session. There were two very well-informed orthopedic surgeons discussing the benefits of gait analysis. It was fascinating to see how far technology has come and how by filming someone walking, doctors can determine what procedures will improve their gait. I had never heard of this process before the conference and even looked further into it upon my return home.

Though all the sessions were informative and the overall experience was life-changing, the most rewarding part of conference came on the last day as I was walking out of a session. A young mother approached me in the hallway asking if I had Spinda Bifida and of course I told her I did. A look of relief swept over her face and she went on to tell me about her daughter who was just like me, a level L4/L5. This meant here daughter could walk on her own with braces or any sort of aid and her biggest problem was bowel and bladder control. As I listened to her speak, I realized her story was almost identical to that of my own. All the surgeries, procedures and life experiences her daughter was going through at that time (she was seven years old), were the same ones I had been through so many years ago. I offered advice about catheterizing and told the mother that she should encourage her daughter to learn to do it on her own as well as giving my personal story about an ACE procedure I had gotten done when I was fifteen and how it changed my life. The woman thanked me and as she took down my number, I felf grateful that I was hopefully able to help out this woman who had never me anyone with the same level of diability that her daughter had.

I made countless connections and acquaintances at conference and look forward to next year. I have brought home a wealth of knowledge I hope to integrate into my life and maybe even into the lives of others in Maine living with the same disability. Conference was a great way to meet people from all over North America and Europe who have Spina Bifida and I am very lucky that I was able to attend. It was amazing to hear that the previously estimated 70,000 Americans living with Spina Bifida was actually 170,000 - a shocking statistic that inspired me to try to get involved with my community and educate people about this birth defect that changes lives every single day.

Massachusetts attendees at the 2009 Conference Luncheon pictured are: (l to r) Seth Campbell; Sandy Campbell; Cara Packard; Matt Neal; Ginny Briggs; Marilyn Briggs; Brian Packard & Jen Fitz-Roy



FOOD
GENETICS
SUPPLEMENTS
Genetics Determine Folic Acid Utilization

Kennedy Family Contributions to the Disabled Community

Eunice Kennedy Shriver, a member of one of the most prominent families in American politics and a trailblazer in the effort to improve the lives of people with disabilities, died at Cape Cod Hospital in Hyannis, MA. Mrs. Shriver never held elective office. Yet she was no stranger to Capitol Hill, and some view her work on behalf of the developmentally challenged, including the founding of the Special Olympics, as the most lasting of the Kennedy family's contributions.

Senator Edward M. Kennedy, a son of one of the most storied families in American politics, was a man who knew acclaim and tragedy in near-equal measure and who will be remembered as one of the most effective lawmakers in the history of the Senate. Perhaps his greatest success on civil rights came in 1990 with passage of the Americans with Disabilities Act, which required employers and public facilities to make "reasonable accommodation" for the disabled. When the bill was finally passed, Mr. Kennedy and others told how their views on the bill had been shaped by having relatives with disabilities.

National Spina Bifida Patient Registry

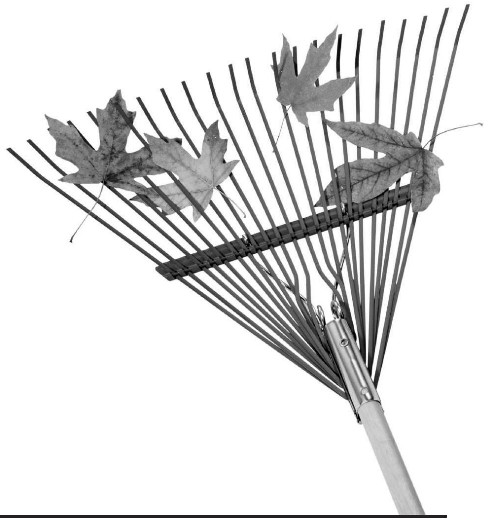
In May, the National Spina Bifida Patient Registry (NSBPR) added the ninth center to its program. "It was great new for those in the Spina Bifida community that this program continues to grow throughout the country. The registry has the potential to help develop and improve methods of care for those living with the challenges of this complicated birth defect," said Cindy Brownstein, President and Chief Executive Officer of the Spina Bifida Association.

The NSBPR is a computerized reporting and database system used to identify current treatments related to some important clinical questions in Spina Bifida. This first step is crucial to a process that will ultimately lead to additional research and to improvements in the quality of care for people with Spina Bifida.

A complete listing of centers and more information on the NSBPR are available on the SBA Web site under
How To Help > Advocacy & Public Policy Priorities.

Thanks to the following who have recently made donations to sbaMass:

- lRed Sox
- Boston Bruins
- Davis Farmland
- Seekonk Speedway
- Plimouth Plantation
- Larz Anderson Auto Museum
- Puppet Show Place
- New England Revolution
- TOMB Interactive Entertainment
- Institute Of Contemporary Art
- Ecotarium
- JFK Library
- Jordan's IMAX
- Gold Level Tix to the Worcester Sharks
- De Cordova Museum
- Dinner for two at Mohegan Sun Seasons Buffet
- Six Flags
- DeCordova Museum
- Zoo New England
- Roger Williams Zoo
- Museum of Science



Summer Picnic Fun!

sbaMass would like to thank
Hannaford Markets
and
Polar Beverages
For their donations to the
Annual Summer Picnic

Thank You Team sbaMass!

Runners raise over $35,000 for sbaMass

Cara Packard

The sbaMass extends its heartfelt thanks to all of our dedicated members of Team sbaMass. On August 9, the Team once again succeeded in running the Falmouth Road Race and raising over $35,000 to help families in our area who are impacted by Spina Bifida.

Race day was beautiful, from start to finish. The perfect weather and very enthusiastic sbaMass cheering section added to the excitement. As always, the highlight was the post-race party, hosted by the gracious Potts family. We were fortunate to have the majority of our 23 member team present to celebrate their great success. The fact that the team was able to raise over $35,000 in this tough economy is a true testament of the team members' dedication and very hard work. SbaMass is extremely grateful for their help.

We are already looking forward to 2010. We are hopeful that the Falmouth Race organizers will continue to allow sbaMass to participate as a charitable organization. We plan to repeat the efforts of our wonderful team members and the expert guidance of Team Captain, Wendy Potts. Their generosity and persistence will enable sbaMass to continue to assist the families of sbaMass in need. Thank you!

Front (l to r) : Jeff Hitchcock; Brian Packard; Katie Packard; Christian Potts; Grace Briggs-Neal; Tara Souza

Center (l to r): Jim Palatine; Bob Bertolino; Mary Honan; Don Martin; Dave Balardini; Wendy Potts; Kathleen Brannigan; Jim Kelly; Matt Neal

Top (l to r): Renee Potts; Jon Paul Potts; Matt Lombardi

Thank you for Donation to the Annual Falmouth Road Race After Race Party

United Sites Services

Port-A-Potties

United SITE SERVICES

Mark Your Calendars for the 2009 sbaMass Holiday Party!

Sunday, December 6, 2009 from 12:30 PM - 5:00 PM
at the Hampton Inn, Natick

Party will include:

- Lunch!
- Fun and Games for all ages!
- Special Holiday Guests!
- Holiday Sing-a-Long
- Yankee Swap for Adults*
  (Bring a wrapped gift worth no more that $10)

  *Adults with S.B. do not need to bring a Yankee Swap item

****Please RSVP by Monday, November 23, 2009****

By Email edugan@sbaMass.org
By phone: (888) 479-1900
Online at: **www.sbaMass.org**

Include the following information in your reply:

- Your first and last name
- Your phone number
- How many people are in your group
- Names and ages of everyone in your group
- Please specify the name of the person with s.b.

Directions to the Party are on web!

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http://www.pressenter.com/~wacma/

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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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CHANGE SERVICE REQUESTED