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New Faces
Join the
sbaMass
team



Letter from the President

Cara Packard

Happy Spring to all of you. Hopefully everyone is drying out from our record rains this month. I am sure that many of us are looking forward to the change over to spring weather. As we move from Winter to Spring, SbaMass is adjusting to new changes as well. In this newsletter you will be able to read about the new faces, new policies and new events coming your way.

First, the Board of Directors is very pleased to welcome new members **Linda Long Belil** and **Jen Fitz-Roy**. Both Linda and Jen joined the Board in January. As you can read in their profiles, both have very impressive resumes and history of service to others. The Board is honored and fortunate to count them among us.

Linda and Jen were quickly pressed into sbaMass service at the Board of Director's January retreat. On that day, the Board spent a Saturday creating a new strategic plan for the organization and revising some of the policies for SbaMass. You can read further in this newsletter about the revised benefits policy and the new Mary Jo Dunleavy scholarships, which will allow SbaMass constituents to attend the National Conference. We are thrilled to be able to honor MaryJo in this way as she helped so many of her patients and families by encouraging them to attend the national conference. The **2010 Conference**, with the theme "Leading the Way to the Future" will take place from **June 27 - 30 in Cincinnati, OH**. We hope that the recipients of the MaryJo Dunleavy Scholarships will enjoy it.

Please mark your calendars for **May 23**, which will be the date of our inaugural Walk-n-Roll event. This year SbaMass decided to adopt the **Walk-n-Roll** program as a fundraising and awareness builder. On Sunday, May 23, we will be walking or rolling around the Endicott Estates in Dedham, MA. The day promises to be fun-filled with activities for all ages, and a nice opportunity for our members to get together. The success of the day will be determined by all of you, so please read information inside this newsletter about how you can participate in or support the Walk-n-Roll.

We hope to see many of you in the coming months and wish all of you a happy, healthy Spring!

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Ms.
Wheelchair
Mass.
Program



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Medical
Research
Corner



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National
Conference
Information



sbaMass

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YEARS

1971-2010

JUMP IN 2009!

Bob Day

Being the second year the anticipations was high and from early signs it appeared that beating last year's numbers would be easy to do. The mood was great and all the radio stations were notified early such that the word would get out to more people. As the months went by the media was silent and no notices certainly meant that the fund raising would be just as difficult as last year. There did seem to be a few more individuals

with interest but as the Months went by the excitement dwindled.

Columbus Day 2009 approached swiftly and the two people left in the game did not give up in heir mission to Jump In and complete the fund raising for Spinsa Bifida.

The day was cool and very windy which made for a very chilly dip in the water and we didn't even have a single media person there. With just the two of us, a friend to take pictures

(not developed yet) and the other jumper's Son we entered the water at 1:30pm (or 1330 military time). For me I did it sort of strange that we collected \$1,330 and entered the water at 1330. Although we didn't quite beat last year's total I do know that we were within \$30 of doing that which is not bad.

So once again Columbus Day has come and gone with hopes that maybe the third time will be a charm.

Bits & Pieces: Getting Around

Ellen Dugan, Executive Director

Web Site Explains College Life to Teens with Disabilities: High school students with disabilities can learn about planning for college at this new site. Videos include interviews with successful college students with disabilities; activities help students explore more about themselves, learn what to expect from college, and discover important considerations and tasks to complete when planning for college. www.going-to-college.org

Social Security Administration Launches Website for People with Social Security Benefits Who Want to Return to Work: The Social Security Administration (SSA) has launched the Choose Work Website for people receiving Social Security disability benefits who want to return to work. The site contains first-person accounts by people who have used the SSA's work incentives; videos, including a Work Incentive Seminar Event; help finding local resources; and more. www.choosework.net

The RIDE Advocacy Project (RAP), an initiative of Boston Self Help Center, is a grassroots community-organizing effort aimed at bringing THE RIDE, the MBTA paratransit service, into compliance with Title II of the Americans with Disabilities Act. RAP members, most of whom have disabilities or chronic illness, are deeply concerned about the poor quality of RIDE service and its negative impact on RIDE users. We are committed to bringing about improvements in RIDE service by building alliances within the larger disability community, as well as among health care and service providers, and together holding the MBTA and its vendors accountable for providing a safe, reliable, accessible service to all eligible riders.

Telephone: 617-277-0080 (messages only)

Mail: RIDE Advocacy Project
c/o Boston Self Help Center
1534 Tremont Street
Roxbury Crossing, MA 02120-2929.

Thank You!

The Board of Directors of the Spina Bifida Association of Massachusetts would like to thank **Susan and Anthony Leo of Peabody and their very generous customers** for their continued support of sbaMass. For many years Susan and Anthony have placed a canister at the register of their superette, T-Stop in Lynn, MA, collecting donations for sbaMass. Once again in 2009 the Leo's and their customers repeated their commitment to sbaMass and donated \$500 to support the programs and services. These donations allow sbaMass to continue to provide much needed support to individuals with Spina Bifida and their families and caregivers.

New Faces Join the sbaMass Operations Team and Board

Wendy Potts joined the staff of sbaMass in November of 2009 as Operations Associate. Wendy became involved with sbaMass in the spring of 2008, when she began organizing Team sbaMass for the Falmouth Road Race.

A graduate of Emerson College with a Bachelors Degree in Media Arts-Television Production, Wendy worked as a Video and Event Producer for Cramer Productions in Norwood until having her first child in 2005. Since then she has been a dedicated stay at home Mother to her 2 sons, Ryan and Casey.

Linda Long Bellil has a background in disability policy, health policy and law and is currently a project director with the Work Without Limits Initiative at the University of Massachusetts Medical School where she oversees projects that promote employment among people with disabilities in Massachusetts. She is also on the faculty of the medical school where she plays a leadership role in educating medical students about working effectively with individuals with disabilities.

Jen Fitz Roy, originally from New Jersey and now living and going to school in Massachusetts, has been an active constituent of the Spina Bifida Association of Massachusetts (sbaMass) since 2002. Jen and her family were members of the Spina Bifida Association of New Jersey from her birth in 1984 until Jen moved to Massachusetts in 2002. Jen currently is a member of the sbaMass Program Committee and involved in events across all age groups. In the past year Jen has been instrumental in assisting sbaMass in developing programs and events to better serve the needs of our constituents. She attends these events, leading discussion in areas of Transition to Adulthood, Self Advocacy, and Understanding Spina Bifida.

Save the Date!
*Annual
Summer Picnic*

**New Date and
Location!**

**July 24th
Hale Reservation
Westwood, MA**

**Look for more information
later this Spring!**

Board Meeting Notes and Updates:

Ellen Heffernan-Dugan, Executive Director

The sbaMass Board of Directors convened on January 30th to review the 2007 Strategic Plan, evaluate the progress toward goals set in that plan and identify new goals for the next 3-5 years.

Goals identified included expanding the fund raising goal to sustain operations through the strategies of developing and implementing a balanced budget, developing and implementing an annual fund raising calendar, including an annual campaign, Walk-n-Roll and pursuing foundation grants. It was evident that these goals are especially important to build and support the organizational capacity that clearly has enabled sbaMass to make many advances in the last several years. In addition the Board identified increasing the volunteer base, expansion and increased diversity of Board members, creating a more robust board committee structure with clear charges, greater online visibility as being essential to the advancement of sbaMass.

In a follow up conference call the Board finalized and approved the goals and strategies in the 2010 Strategic Plan. The board intends to continue discussion of strategies to achieve the other goals at upcoming board meetings. The retreat was productive and achieved the objectives of educating and energizing the board, building collegiality and establishing goals and strategies for 2010.

The sbaMass Board of Directors and staff would like to acknowledge the Blue Cross/Blue Shield Catalyst Foundation for their support of this endeavor.

The sbaMass Board continues to meet on a quarterly basis. Upcoming meetings are scheduled for May 6th, August 3rd and November 2nd in Waltham. All constituents are welcome to attend. To confirm date, location and time or if you have items you would like placed on the agenda, please contact Ellen Heffernan-Dugan at edugan@sbaMass.org or 888-479-1900. Agendas will be posted on the sbaMass website www.sbaMass.org and the Parents and YAG list serve prior to upcoming meetings.

Ms. Wheelchair Massachusetts Program

Santara Sen

The Ms. Wheelchair Massachusetts program is an opportunity for women between the ages of 21 and 60 years old with physical disabilities to become advocates for people with disabilities. Each year a pageant is held at the Bayside Expo Center in Boston, and women who apply to compete participate in personal interviews, on-stage interviews and also give a two minute platform speech on a topic of their choice. The judges also take into careful consideration each contestant's personal, vocational and academic accomplishments up until the pageant as well as any current work they are doing on behalf of people with disabilities. After all is said and done, the judges deliberate and a winner is chosen.

The person selected as Ms. Wheelchair Massachusetts (or their given state) takes on the responsibility of advocating for people with disabilities all across their home state. They participate in events at their State House; meet with legislators in an effort to improve programs and services in place to help people with physical disabilities lead healthy and successful lives. She also fights for services and programs that are not in place at all, that should be. Ms. Wheelchair Massachusetts also spreads awareness of disability issues by doing both radio and print interviews. Finally, through her example Ms. Wheelchair Massachusetts proves that women with disabilities are every bit as successful and happy as women without disabilities.

There is also a Ms. Wheelchair America program where women who have won titles for their home states all come together and compete for the national title. Currently there are about thirty five of the fifty states that participate at the national level. The state coordinators have the great responsibility of putting together the details for the national pageant each year. This is an amazing opportunity for all, yet it comes with the responsibility of fundraising the cost of the travel and hotel expenses for yourselves and your guest(s). This can seem like an overwhelming task but the Board Members of your state are willing to assist you with fundraising ideas.

I have participated in the Ms. Wheelchair Massachusetts program for the past two years. The first time I considered more of a practice run and a good experience, even though I knew I wanted to be an advocate for people with disabilities. It was important to me to have this role because I know when my parents first found out that I was going to be born with a disability (spina bifida), they were so overwhelmed with the news, and at the time they did not know who to turn to for help or advice and felt very much alone. I do not want other families to go through that; instead I want them to know that there are resources and people who can help them.

As disappointed as I was about not placing in the top three the first time around, I knew there would always be next year and sure enough when the time came to apply for the 2010 pageant, I was "ready to roll"! By this time, I had more life experience, having graduated from college and more opportunities working with children with disabilities. I also had knowledge of the ADA New England, and ADA laws because I took a college course on disability issues a few years ago and signed up to be a part of the ADA New England's Student Advisory Group, which helps people with disabilities share their stories through video. These factors and my own confidence and perseverance helped me secure the title of Ms. Wheelchair Massachusetts 2010.

This year I hope to not only advocate for the rights of individuals with disabilities and their families, but to convey the message that people with disabilities are just like everyone else, except that we get around differently. I want to work towards eliminating stigma associated with disability about what we "should do" and replacing it with the things that we "can do". Finally, I am excited to advocate at the State House for different disabilities including Deaf/Hard of Hearing, Blind, Spina Bifida, Autism and more.

For more information on the Ms. Wheelchair Massachusetts program and competition details, please visit the website: www.mswheelchairmass.org.



Finding a Successful Bowel Management Program: Avoiding Surgery

Ginny Briggs, Ph.D.

Bowel control issues are one of the biggest challenges the Spina Bifida (SB) population faces everyday. For parents, it's difficult because we have to help our children handle the problem as they're growing up, especially when they reach an age that their peers may notice they are different in more than one way. For older children and adults, it needs to be addressed (and effectively) to be able to blend into settings such as a workplace or social event. It is often embarrassing for both SB children and SB adults, and that is one of the reasons it is essential to work with their physicians to solve the problem. There are several ways someone can achieve continence and stay "clean". However, it's not the same for everyone, and may require a lot of trial and error before the right program or treatment is found. In a study published in 2009, bowel management programs were examined in a group of people with a number of different conditions that affected bowel control, including Spina Bifida.

There were 294 patients in the study. The study divided the patients up into two groups, those with a tendency toward constipation, and those with a tendency toward diarrhea. The treatment that was used consisted of various enemas. They used different combinations of saline, glycerin, soap, phosphate and Fleet/24. Six of the patients had previously had the ACE procedure, and 13 patients had colostomies. They also received treatment in the study.

The researchers considered bowel management to be successful when the patient's underwear was totally clean for 24 hours. The whole process of the enema and emptying of the colon did not take any longer than 1 hour (after receiving the enema, the patient was instructed to hold it for 10 minutes, then sit on the toilet for up to 45 minutes). To monitor how well each patient responded to different solutions in their enemas, the researchers used x-rays. If a patient was not emptying well enough, they added different solutions until the colon began to empty.

The success rate was highest in the constipated group (98%) as compared to the diarrhea group (84%). The study found several interesting things about enema treatments.

1. Monitoring the colon using x-rays is the best way to determine what kinds of enemas work best for each patient. This reduces a lot of guesswork that goes into figuring out the right kind of enema.
2. Normal saline solutions are best, compared to a homemade mixture of salt and water. The mixture was not prepared correctly in two of their study patients, which resulted in emergency room visits.
3. Phosphate in enemas was found to cause colitis (swelling and irritation of the colon) in some patients. Because of this, the researchers now use phosphate as a last resort (after they have tried glycerin and liquid soap).
4. The treatment was also introduced into stomas. Many patients felt that was successful for them because they had empty stomas for 24 hours, which made it possible to be involved in sports and other activities without worrying about leakage.

The overall conclusion of the study was that tailoring the enema treatment and diet for each individual is the key to a successful bowel management program. Also, the best way for clinicians to evaluate the "cleaning effect" of an enema is through x-rays. The researchers also felt that each patient should take the time to explore different combinations of treatment, before resorting to surgery. These results can help both parents of SB kids and adults with SB talk to their doctors about how they can achieve a successful bowel management program.

Reference: Bischoff A, Levitt MA, Bauer C, et al. Treatment of fecal incontinence with a comprehensive bowel management program. *Journal of Pediatric Surgery*, 2009 Jun;44(6):1278-83; discussion 1283-4.

SBA Annual Conference: sbaMass Assistance

The sbaMass is offering two programs to assist constituents and /or professionals in attending the SBA Conference:

The **sbaMass Conference Scholarship** provides up to \$1500 for an individual with Spina Bifida or family to attend conference.

Mary Jo Dunleavy Conference Award (see below), in memory of Mary Jo Dunleavy, RN, coordinator of the Spina Bifida clinic at Children's Hospital sbaMass is offering two awards, \$1500 each, to attend the SBA Annual Conference.

These awards are available to an individual, family or professional. For an application and additional information regarding these awards, log onto www.sbaMass.org or contact Ellen Heffernan-Dugan at edugan@sbaMass.org or 888-479-1900. **This year the conference is being held in Cincinnati, Ohio June 27th - 30th.** For more information regarding the conference, sessions and other events log onto www.sbaa.org.

The deadline for applications has been extended to April 15th for both programs.

Mary Jo Dunleavy Award

Application Deadline April 15th

Mary Jo was truly a gift to the Spina Bifida Community and her passing has left a void which will be difficult to fill. The Spina Bifida Association of Massachusetts, through an effort coordinated amongst the very many who wish to honor her, have dedicated an SBA Conference Award in her name. Mary Jo believed it was important for individuals living with Spina Bifida and their families to attend the annual SBA Conference, that the benefits were many. For additional information or an application log onto www.sbaMass.org or contact Ellen Heffernan-Dugan at 888-479-1900 or edugan@sbaMass.org.

Thanks!

The sbaMass gratefully acknowledges the ongoing support of **The Original Wedding Expo**.

The Original Wedding Expo features a collection of wedding planning professionals: everything from cakes and favors to photographers, florists, reception sites, bridal and tuxedo shops, bands and Disc Jockeys, transportation and invitation companies and videographers. There is a fabulous fashion show, great musical performances and wonderful food to sample. The Original Wedding Expo generously makes available exhibit space to sbaMass, several times a year. This opportunity allows sbaMass to reach women of child bearing years and their partners regarding the benefits of folic acid. The sbaMass is appreciative of the opportunity to extend our outreach in this critical endeavor.

The Expo is held in various locations in Massachusetts throughout the year. For more information about dates and locations log onto www.originalweddingexpo.com.

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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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